PRELIMINARY REPORT

January 27, 1998
Masonic Auditorium, San Francisco

WILLIE L. BROWN, JR.
Mayor

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OFFICE OF THE MAYOR
SAN FRANCISCO

WILLIE LEWIS BROWN, JR.

Welcome

Welcome to San Francisco's Summit on AIDS and HIV. Your concern and participation are critical to the success of this conference and the implementation that will follow.

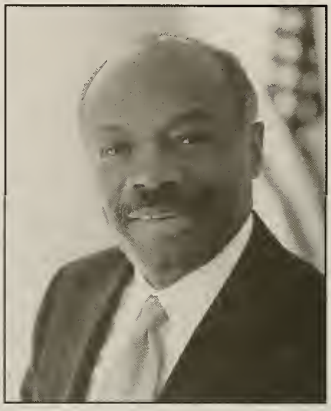
We all know how the City of San Francisco has been severely impacted by the AIDS epidemic. The devastating effect upon our diverse communities, the tremendous financial resources that have been expended, and most importantly, the great feelings of pain and loss we all have experienced are immeasurable.

San Franciscans have battled this disease for over a decade and a half. Many have passed on. Many have suffered burn-out and heartbreak. Many more are still in the fight. Through the hard work, vision and compassion of people such as yourself, we developed a network of care that has become a world-wide model – one which must continue to evolve.

Clearly, within the last year, we have seen many important, positive developments in the epidemic. With the advent of protease inhibitors and triple-combination therapy, many people living with HIV and AIDS are now looking with a new sense of hope toward the future. Prolonged life, and improved quality of life, is much to celebrate.

We can be very proud of the fact that in our City, everyone who needs and wants to avail themselves of the new medications can do so, regardless of ability to pay their extremely high cost. There are unfortunately few other places on the globe where this is true.

Along with the opportunities presented by these promising medical treatments, many new challenges confront us as a City. The drugs are not a cure for AIDS and they do not work equally well for all people. Our commitment to prevention, affordable housing, access to healthcare, and providing for the basic survival needs of all people living with AIDS and HIV will not diminish, but will continue to grow as people live longer and infections continue. Medical advances have created the need for new kinds of social services, such as employment programs.



I have called this Summit to focus attention on the emerging issues in this changing epidemic.

Today, we see the fruition of many months of hard work by a large number of talented and experienced individuals, who have identified and analyzed the issues we will discuss. I am deeply grateful to all of the Steering Committee and Subcommittee members who have provided their time, energy, talent and leadership ability to this community-based planning process. This is additional evidence of the commitment, vision and activism that the citizens of San Francisco have shown throughout this epidemic.

The recommendations in this report and today's presentations will enable us to refine our system of care and continue to provide the level of service to which we are all committed.

Let me assure you this will not be another meeting that generates a report to be filed away and quickly forgotten. I am strongly committed to an implementation plan that will analyze and prioritize the recommendations made here, determine how and when they will be carried out, assign who will be responsible for them, and secure the necessary funding.

I am pleased to be able to announce today several specific policy initiatives that will be undertaken to put words into action:

Mayor's AIDS Leadership Forum

The changes in social service needs resulting from advances in AIDS medical therapies have underscored the need to strengthen the planning capacities of community-based AIDS service organizations to ensure that San Francisco's Model of Care and its prevention messages remain fully responsive to the needs of people with HIV and AIDS.

Accordingly, I am creating the Mayor's AIDS Leadership Forum to engage the leadership of these organizations in the common challenges and opportunities resulting from changes in the epidemic and to help implement this Summit's recommendations. Membership in the Forum, which will

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convene quarterly, will include the Board Presidents of the more than one hundred agencies providing AIDS services in San Francisco. The Forum will provide technical assistance, a planning grant program and opportunities for information-sharing and problem-solving as means to help improve the efficiency and quality of San Francisco's AIDS service system. I want to thank Macy's Passport and Glaxo-Wellcome for generously providing the initial funding to launch this initiative, in addition to their financial support of the Summit.

AIDS Coordinator

I will appoint a senior-level staff person in the Mayor's Office to oversee the implementation of Summit recommendations, as well as other AIDS-related issues that require Mayoral leadership. The duties of this newly-created position will include:

- Reviewing and prioritizing Summit recommendations, identifying budgetary requirements and possible sources of funding, creating timelines and action plans, and recommending assignments of responsibility.
- Monitoring implementation by the Department of Public Health, other relevant City departments and City-funded contractors.
- Staffing the Mayor's AIDS Leadership Forum.
- Serving as my liaison to the HIV Prevention Planning Council and Mayor's HIV Health Service Planning Council, with responsibility for coordinating the implementation of the Summit's approved recommendations with the on-going planning conducted by these bodies.
- Serving as community and press liaison on AIDS policy issues.

Progress Meetings

I will convene quarterly meetings of all heads of City departments who are assigned to carry out Summit policies to monitor their progress, as well as to help integrate AIDS services more fully with other City programs. The results of these meetings will be communicated in reports to the community.

I will also meet with the Summit Steering Committee, and other appropriate persons, six months after the Summit to assess what has and has not been done.

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Media Campaign

People with HIV and AIDS who are now able to maintain employment as a result of improved health due to the new therapies still face barriers to entering or re-entering the workplace that can be overcome with appropriate services. In connection with the establishment of an HIV/AIDS Employment Development Unit in the Department of Public Health, as recommended in this report, I am pleased to announce a media campaign to create awareness of programs and resources that will help people with HIV and AIDS succeed in the workplace.

Saatchi & Saatchi, one of the world's leading advertising agencies, has made this campaign possible by generously agreeing to provide the creative work on a *pro bono* basis. The campaign will include television and radio public service announcements, as well as print advertisements, bus signs, bus shelter posters and print posters. In addition to Saatchi & Saatchi, I want to thank IDEAS: for advertising and design in San Francisco, which will donate its services in creating a website as part of the campaign, as well as Jim McBride for his outstanding work in conceiving and developing this campaign.

Finally, I would like to thank the corporations and foundations that shared our appreciation of the need for this Summit and contributed generously to make it happen.

Vigilance, determination and hope will see us through this epidemic. Within the last year, we have taken a positive turn in the course of HIV. Eventually, we may make our way to a cure or vaccine. But until then – or perhaps forever – we must continue to maintain the leadership position that the great City of San Francisco has been recognized as providing.

Willie L. Brown, Jr.
Mayor
City and County of San Francisco

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Program

7:30 – 8:30 am	Registration, Continental Breakfast
8:30 am – 12:15 am	Opening Remarks by Summit Co-Chairs *Marcus Conant and Thomas Coates*
	Address *Mayor Willie L. Brown, Jr.*
	Report on Epidemiology of AIDS and HIV in San Francisco *Mitch Katz, M.D.* *Interim Director of Health*
	Presentation and Discussion of Subcommittee Recommendations:
	New Directions in Prevention *Ellen Goldstein, Steve Lew, Lisa Moore*
	Access to Therapy *Martin Delaney*
	Adherence to Treatments *Margaret Chesney, Marcy Fraser, Billy Pick*
	Insurance Issues *Steve Becker, Dave Mahon, Herminia Palacio*
12:30 – 2:00 pm	Lunch Fairmont Hotel Grand Ballroom

2:15 – 5:15 pm

Remarks
Helene C. Gayle, M.D.
Director, National Center for HIV, STB and TB Prevention, Centers for Disease Control and Prevention

Presentation and Discussion of Subcommittee Recommendations:

Testing, Surveillance and Reporting
Eileen Hansen, Steve Heilig, Hank Tavera

Workplace Entry and Re-Entry
Ron Hill, Amanda Feinstein, Galen Leung, Jim McBride, Paul Vander Waerdt

Housing
Mark Dunlop, Chris Harris, Louis Sands

Other Issues
Matthew Sharp

The Future of Federal AIDS Funding
Steve Morin

Closing Remarks
Mayor Willie L. Brown, Jr.

Sponsors

This Summit was made possible by generous funding provided by:

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for their donation of in-kind support of this Summit:

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San Francisco Chamber of Commerce
Community Consortium

...and the many organizations which provided mailing lists for invitations

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UCSF Center for AIDS Prevention Studies

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for helping to initiate the planning process for the Summit

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Anne Kronenberg, Department of Public Health
Sharon Johnson, Office of Senator John Burton

...and to the many City employees and others
who volunteered their time at the Summit

Introduction

Purpose

The combination antiretroviral therapies that have become available in the past two years have revolutionized the treatment of AIDS and HIV. Along with advances in the prevention and treatment of life-threatening HIV-related infections, treatment with protease inhibitors has dramatically reduced deaths from AIDS, improving the health and extending the lifespans of many people living with the disease. At the same time, prevention programs have succeeded in lowering the rates of new infections.

No one has yet been cured of AIDS. But these developments offer real hope for the first time in the nearly two decades of the AIDS epidemic. They also present serious new challenges.

From the earliest days of the epidemic, San Francisco has taken the lead in crafting a compassionate and comprehensive program to fight this disease, creating a full spectrum of services to prevent HIV infection and care for those who are ill. Now, as more people are living longer with HIV, the demand has increased for existing services and needs have developed for new programs we could not have foreseen just a short time ago.

This Summit will examine the challenges and opportunities created by these new medical advances and recommend policy changes so that San Francisco continues to respond effectively in the new AIDS environment.

The Summit was not intended to be a comprehensive conference on all AIDS-related issues, but rather to focus on a manageable number of significant issues in which the City of San Francisco can make a real difference. These issues include:

- How can we make treatment more accessible to those who might benefit from it?
- How can we help those on treatment adhere to the rigorous regimens?
- How can we assure quality medical care in the era of government funding cuts and managed care?
- How do we respond to calls for mandatory testing and reporting?
- How can we help people with AIDS secure and maintain successful, productive employment?

- What new approaches to prevention should be undertaken to deal with shifting demographics and possible relapses into risky behavior?
- How can the growing number of people living with HIV be assisted with affordable housing?
- What is the likely future of public and private funding for AIDS, amidst the common perception that the crisis is over.

As we deliberate these and other related issues, we must recognize that the progress in AIDS treatment has negative side effects, just as the medicines themselves do. Many people have been left behind in the treatment euphoria.

The drug regimens are extremely arduous and expensive, often inaccessible or impractical. For many people they are ineffective, even in the short term, and there is reason to doubt their performance over long periods of time.

While the City's rate of new infections has decreased, it has not done so equally among all population groups. Increasingly, the demographics of the epidemic are shifting to people who are more disenfranchised in our political system and harder to reach by prevention efforts. Many of the people most at risk of infection have multiple health and psychosocial issues, requiring greater integration of AIDS services with other public health and social services.

As AIDS potentially becomes a manageable, long-term chronic disease, the flaws of our nation's "system" of healthcare will increasingly impact people with HIV and AIDS. It has often been suggested that AIDS "should be treated like any other disease." The truth is just the opposite: other diseases should be treated like AIDS, with the same comprehensive and compassionate approach that has been shown to be effective in this epidemic.

While most of our recommendations are specific to the City of San Francisco, and reflect our unique government structure, political climate and AIDS epidemiology, we are hopeful that they will provide useful models for those fighting AIDS in other cities and nations.

Although the global epidemic is beyond the scope of this conference, we must keep in mind that millions of people within our own country are not so fortunate to have the quality of treatments and services that are readily available in San Francisco. And the vast majority of the estimated 23 million people infected with HIV worldwide have no access to the drugs and healthcare that could save their lives.

This Summit is an opportunity for all concerned people to participate in defining the policies that could very well make the difference between life and death for many people well into the 21st century.

Process

Recognizing the changes in the epidemic and emerging needs, San Francisco Mayor Willie L. Brown, Jr., called in mid-1997 for a Summit on AIDS and HIV to update the City's model of services.

Mayor Brown appointed Drs. Marcus Conant and Thomas Coates of the University of California, San Francisco, to chair the Summit. A Steering Committee of leading experts and activists, including numerous persons living with HIV, was formed to oversee the project.

Subcommittees were appointed in seven issue areas, with memberships broadly representative of San Franciscans working on those issues. Over the past several months, the subcommittees studied and debated the issues, and, in many cases, held public meetings to solicit comment. Additionally, several individuals were invited to study issues in which they have extensive experience.

The results of the work of over 100 people is presented in this preliminary report and will be summarized in presentations at the Summit.

Mayor Brown, determined that all ideas be put on the table for discussion, did not want to edit, approve or reject any of the text or recommendations in advance of the Summit.

Please note that not every member of the Steering Committee or subcommittees agrees with every statement or recommendation made throughout this report. The opinions expressed in each section are those of the specific subcommittee or individual listed at the end. In some cases, minority opinions within a subcommittee are noted.

Further public comment is welcomed. Subcommittees will take questions and comments after their presentations at the Summit, although time constraints will necessarily limit the number of people who can speak. At the back of this report is a form to submit comments in writing at or after the Summit. This oral and written testimony will be incorporated into the final report on the Summit, scheduled to be published this Spring.

Mayor Brown has expressed his commitment to an implementation plan to follow up on the more than 100 specific policy recommendations made here. We recognize that many of the recommendations are controversial, expensive or complex. We commend the Mayor for his continuing strong personal leadership on this issue.

The future of AIDS is sure to be as unpredictable as the epidemic has been in the past. The recommendations made here could soon be outdated if there are significant changes in key factors, such as new therapies, increased drug-resistant strains, behavioral relapses into risky behavior, migration rates of infected individuals into San Francisco, the level of federal and state commitment to research and treatment, and policies of the insurance industry and major employers.

That is why this Summit is just the beginning of the analysis, dialogue and action that needs to be undertaken for San Francisco to continue to be a model in the fight against AIDS.

– Dick Pabich
Summit Coordinator, Person living with AIDS

Epidemiology of HIV and AIDS in San Francisco

Good policy on HIV and AIDS issues requires understanding the epidemiology of HIV and AIDS in San Francisco.

The epidemic has had a devastating effect on San Francisco. A small county with a large population of gay and bisexual men and injection drug users, San Francisco has been hit particularly hard among American cities. As of December 31, 1997, we have had 24,962 cumulative AIDS cases and 16,999 deaths due to AIDS. We have lost our friends, our partners, our family members, our co-workers, our patients, our neighbors, but not our determination to see the end of this epidemic.

There are reasons to feel hopeful in the face of so much loss. This is well illustrated in *Figure 1*. We see the steadily increasing number of AIDS cases beginning in 1980 and peaking in 1982, with over 6,000 cases diagnosed in that year. Since 1992, we have seen a dramatic drop in the number of new cases to under 2,500 by 1996.

Several factors account for this drop. From the newspaper reports, you would think that most of the drop is due to the advent of highly effective antiretroviral treatment. However, protease inhibitors were not introduced into clinical use until the Winter of 94-95, and relatively few persons had actually used these drugs prior to 1996. Most of the reduction is due to the effective prevention efforts that were launched in the 1980's. In the early 1980's, prior to our ability to test for the presence of HIV antibodies, there were approximately 8,000 new infections per year. By 1984, this had been reduced to under 1,000 infections per year due to the community mobilization efforts, especially in the gay and bisexual male community.

Because the average time between infection and development of AIDS is ten years, it took us about ten years to see the effect of these successful prevention efforts. Some of the peak is also due to the implementation of the new AIDS definition in 1992, which resulted in people being diagnosed about 18 months earlier than they otherwise would have been under the old definition.

You can also see from *Figure 1* that we have also had a peak in deaths due to AIDS. The peak occurs in 1994, about 2 years after the peak in AIDS cases. Again, this is very consistent with the natural history of HIV. The average survival time between AIDS and death hovered around a year and a

half to two years in the era prior to the development of highly effective retroviral therapy.

The most important line in *Figure 1* is the top one: the number of persons living with AIDS. With all of the news reports focusing on the decreases in the numbers of AIDS cases and AIDS deaths, we have been very concerned that there would be a weakening of the commitment to the crucial services that are needed by HIV-infected persons. What the top curve shows is that, while the number of news AIDS cases and deaths is decreasing, the number of people living with AIDS is increasing. This is due to the improved therapy of HIV. However, this improved therapy is costly. Moreover, many of the people who depend on HIV treatment to keep them healthy also need other services, such as food, housing, mental health and substance treatment.

Figure 2 shows annual AIDS incidence by ethnicity among men. You can see that the incidence for men is higher for whites than for African-Americans, and Latinos and Asian Pacific Islanders. The incidence was also higher for whites than for Native Americans in the earlier years of the epidemic and about the same now. For all ethnic groups, AIDS incidence has been decreasing, although the drop has been a great deal steeper for whites than for the other ethnic groups. Turning our attention to women, *Figure 3*, we see that incidence is highest among African-Americans and Native Americans. Incidence is lower among Latinas, whites and Asian Pacific Islanders. Decreases in new AIDS cases have not been as steep among women as men.

The pie charts in *Figure 4* give you a sense of recent changes in the demographics of the AIDS epidemic. On the left, you see the breakdown of cumulative AIDS cases by ethnicity. On the right, you see the breakdown of 1996 AIDS cases by ethnicity. You can see that a larger proportion of 1996 cases are African-American, Latino or Asian Pacific Islanders, compared to cumulative AIDS cases. In *Figure 5*, you can see that women make up a larger proportion of the 1996 cases than our cumulative cases.

The pie charts in *Figure 6* show you other trends in our epidemic. A larger proportion of 1996 cases are injection drug users and a smaller proportion are gay and bisexual men. Still, in 1996, 87% of San Francisco AIDS cases are men who have sex with men or are men who have sex with men and use injection drugs. In *Figure 6*, you see that the proportion of cases among women who are injection drug users is also increasing.

Finally, *Table 1* shows you our estimates of the prevalence and incidence of HIV in San Francisco. Prevalence refers to all people who are

alive and are HIV-infected. Incidence refers to people who become newly infected that year. These estimates are based on a consensus conference sponsored by your Health Department. Researchers throughout San Francisco came together to review available data on our epidemic. Looking at the bottom, you can see that we believe there are approximately 15,260 persons in San Francisco who are HIV-infected, and approximately 500 new infections per year. You can see in the second column that the prevalence of HIV is very high among men who have sex with men (30.5%), and also high among injection drug users (12%).

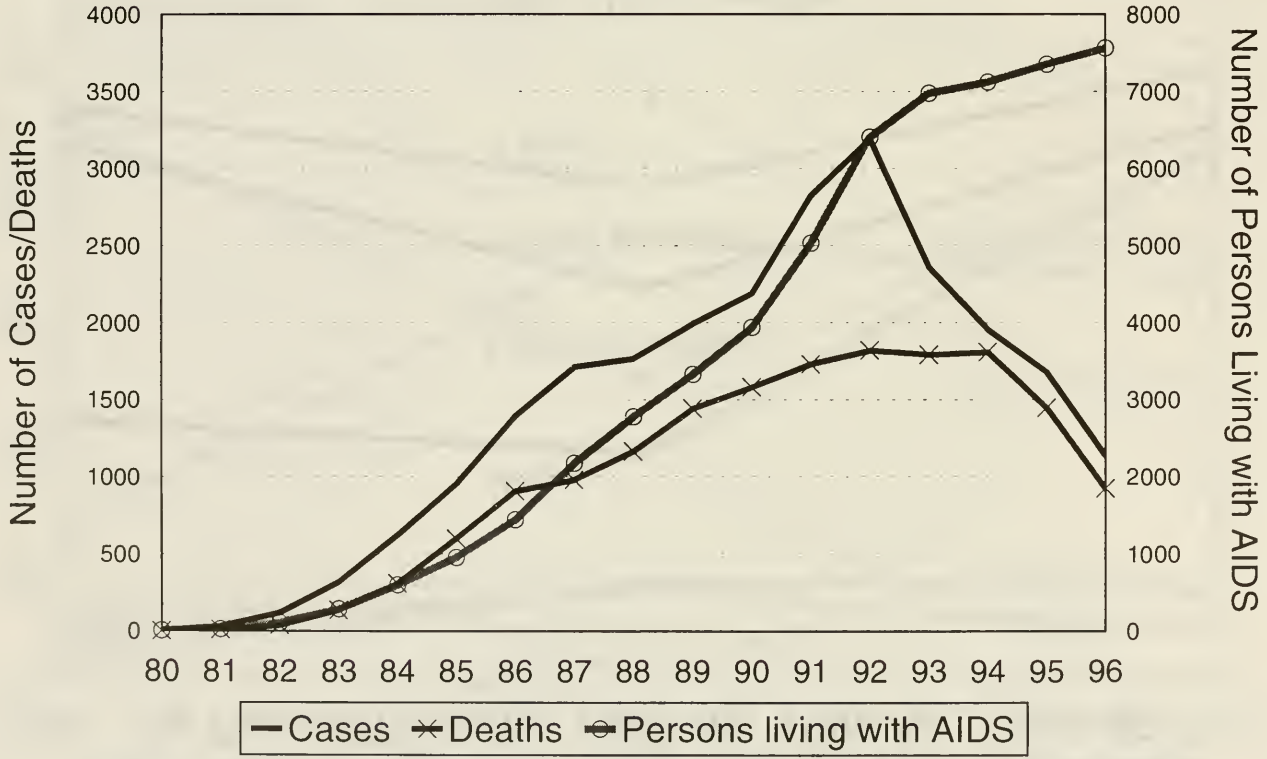
What are the major epidemiological trends telling us?

- Prevention works, but we have to do more, especially for those groups that have not benefited as much from the early prevention efforts, including women, people of color, injection drug users, and young men who have sex with men.

- Although there are dramatic drops in new AIDS cases and AIDS deaths, the number of persons living with AIDS is increasing, so we need more, not fewer, services.

– Mitch Katz, M.D.
Interim Director of Health

Figure 1
AIDS Incidence, Mortality, and Prevalence
San Francisco, 1980-1996



San Francisco Department of Public Health, 11/30/97

Figure 2
Male AIDS Cases per 1000 Men in San Francisco by Race/Ethnicity, 1980-89, 1990-93, 1994-96

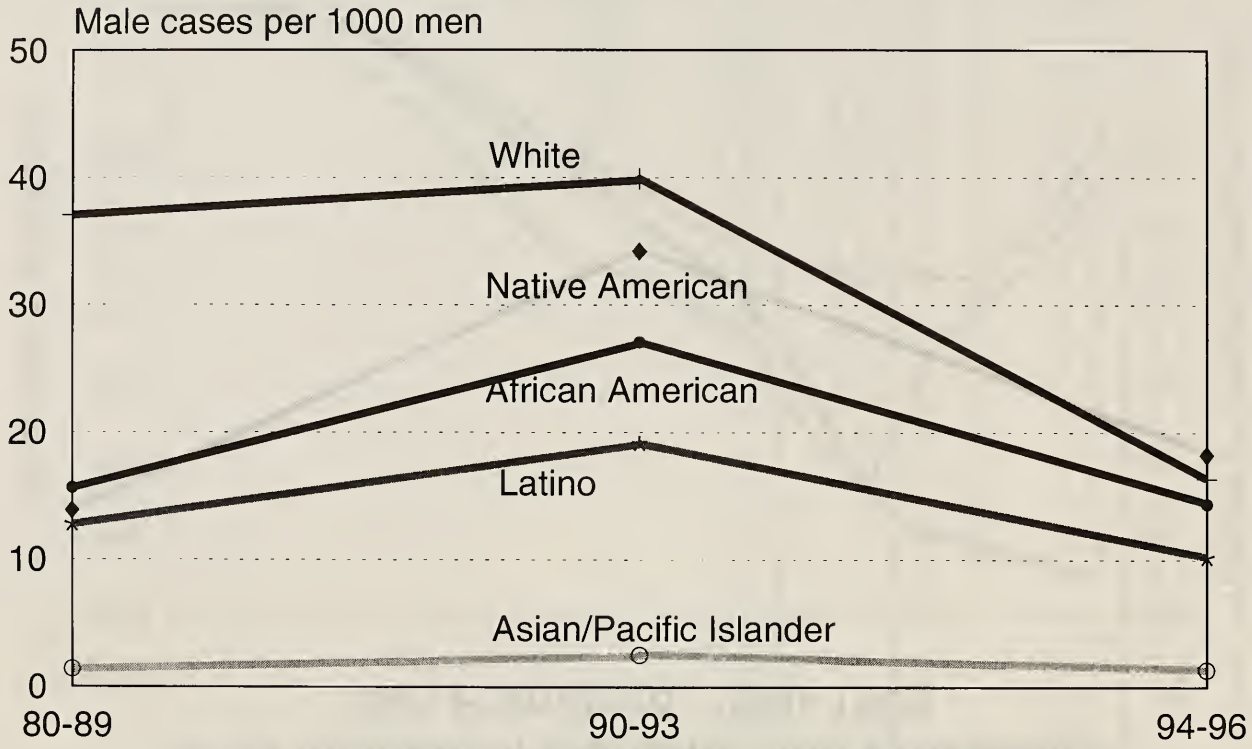


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Figure 3
Female AIDS Cases per 1000 Women in San Francsico by Race/Ethnicity, 1980-89, 1990-93, 1994-96

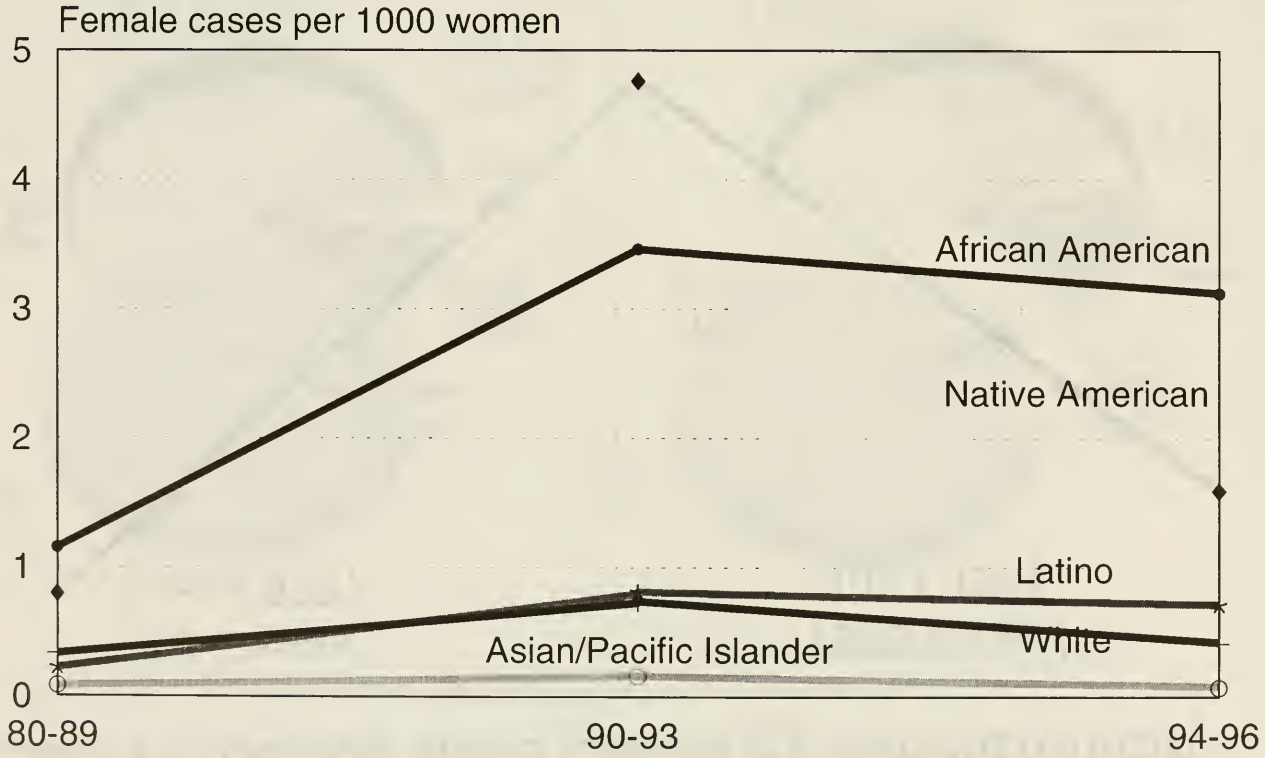

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Figure 4
San Francisco AIDS Cases by Race/Ethnicity

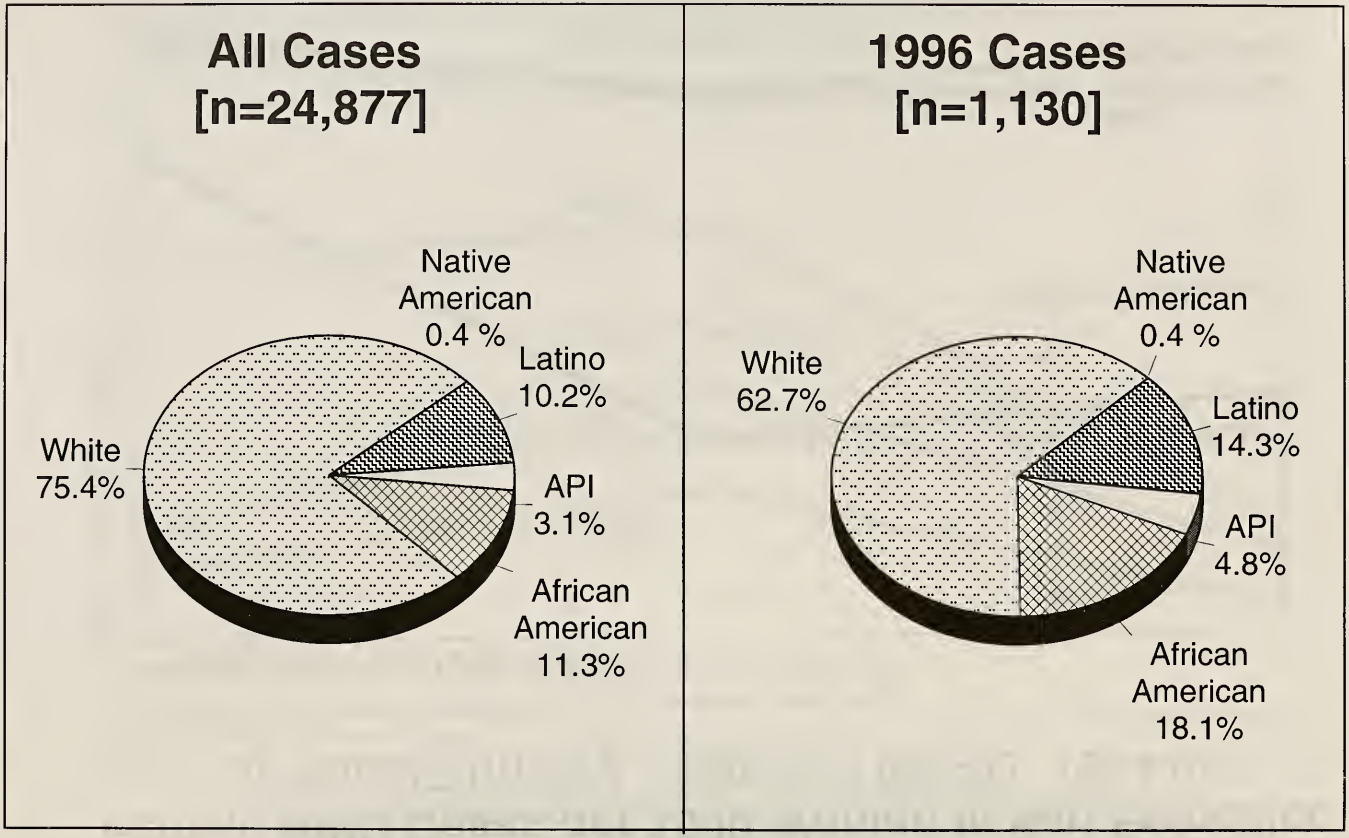

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Figure 5
San Francisco AIDS Cases by Gender

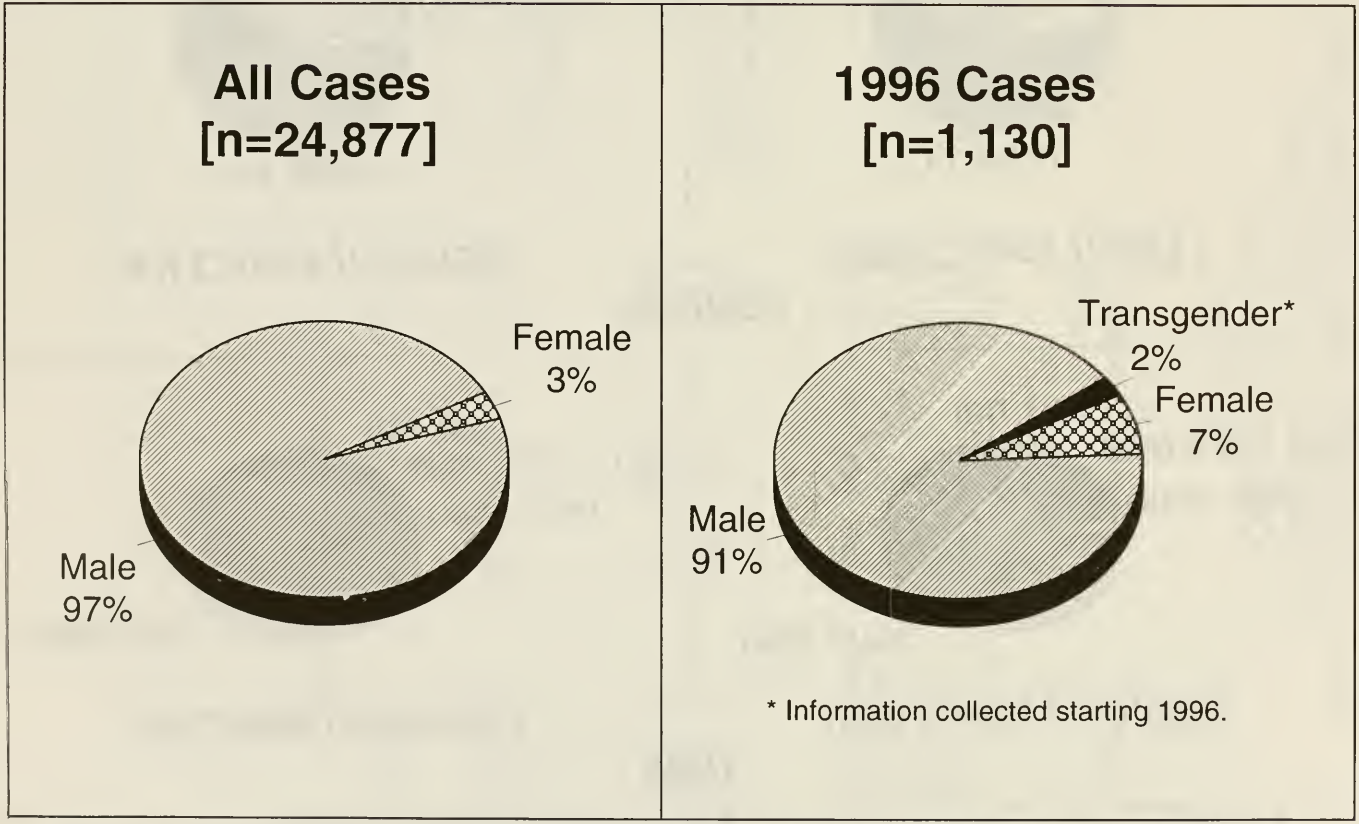

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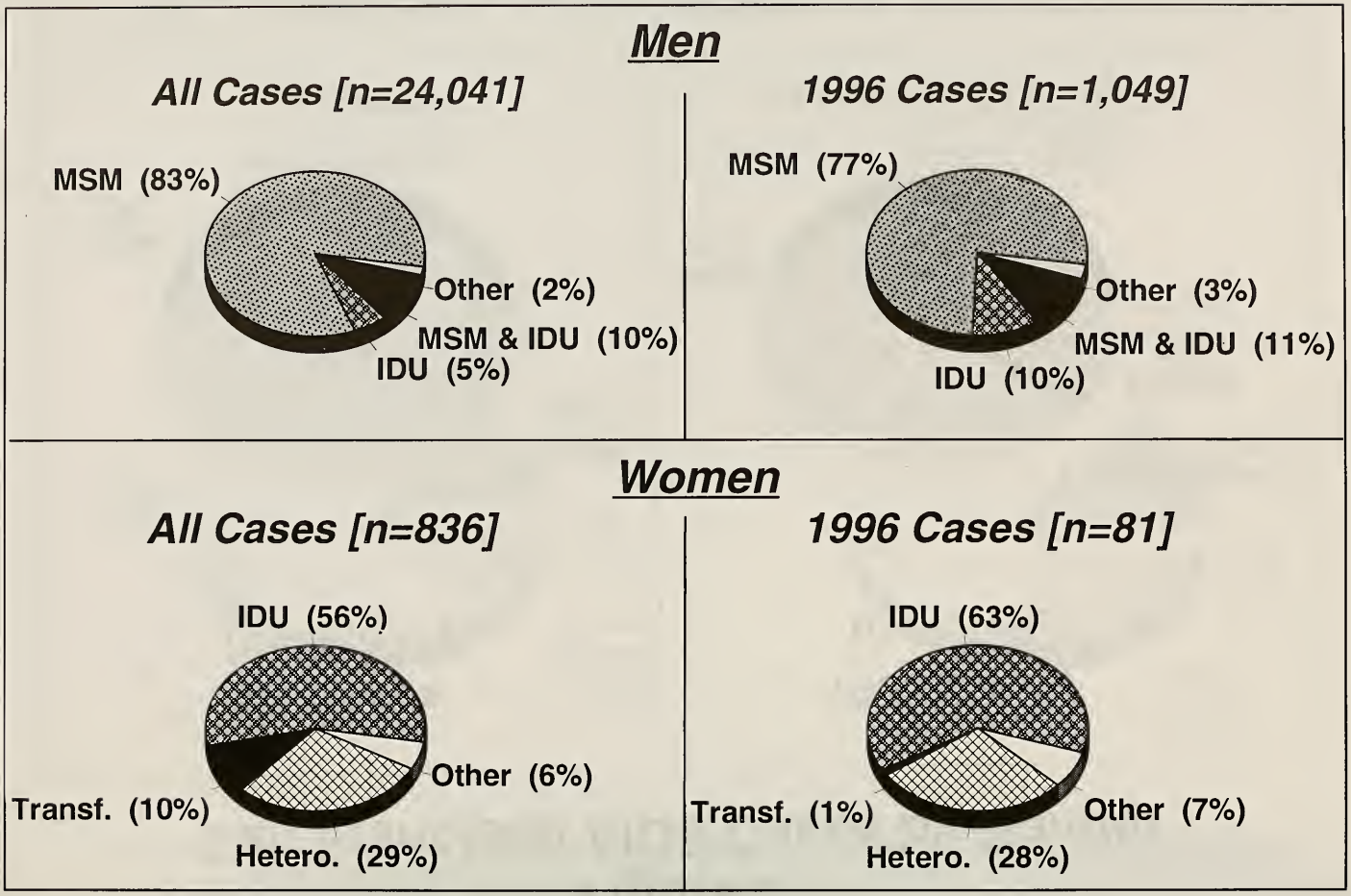
Figure 6
San Francisco AIDS Cases by Transmission Category



San Francisco Department of Public Health, 11/30/97

1997 HIV CONSENSUS MEETING ON HIV PREVALENCE and INCIDENCE IN SAN FRANCISCO

May 12, 1997

Risk Group	Population Size	Prevalence		Incidence	
		N	%	N	%
MSM, MSM/F					
Non-IDU (subtotal)	39,000	11,700	30%	283	1.1%
Young (<30)	*6,300*	*945*	*15%*	*64*	*1.2%*
Older (30+)	*32,700*	*10,755*	*33%*	*219*	*1.0%*
IDU	4,100	1,435	35%	53	2.0%
Subtotal	**43,100**	**13,135**	**30.5%**	**336**	**1.1%**
Heterosexual Male & Female IDUs					
Heterosexual Male	8,500	1020	12%	76	1.0%
Women	4,500	540	12%	41	1.0%
Subtotal	**13,000**	**1,560**	**12%**	**117**	**1.0%**
Other Adult/Adolescents					
Heterosexual Male	250,000	150	0.06%	15	.006%
Women	300,000	300	0.10%	30	0.01%
Trans/Blood disorders		50		1	
Infants/Children (<13)	105,000	65	0.06%	1	0.01%
Total		**15,260**		**500**	

New Directions in Prevention
Subcommittee Report

Introduction

San Francisco's Department of Public Health currently funds HIV prevention programs targeting all at-risk populations in the City. The Department awards funds to 27 community-based agencies and 6 programs in its AIDS Office to conduct HIV prevention activities.

Approximately $13 million in federal, state and local funds are spent annually in San Francisco on these HIV prevention programs. The activities and target populations are prioritized by the HIV Prevention Planning Council, San Francisco's community advisory body for HIV prevention. The Planning Council prioritizes resources to people at highest risk with culturally competent prevention programs.

Ten types of interventions are funded to address people at various levels of risk and with different cultural, psychosocial, economic, gender and age-specific needs. Just over half the funding supports HIV antibody testing and counseling, multiple session groups, and outreach. When looking at HIV prevention programs by the risk behaviors of the clients they reach, over half of the funding targets gay and bisexual men (with nearly 20% of that funding addressing the needs of gay and bisexual men who inject drugs), over 30% specified for programs to reach heterosexual injection drug users, and 10% of the funding targeting programs for heterosexuals who do not inject.

HIV prevention programs are funded to reach people of all ethnicities: African American, 27% ; Asian and Pacific Islanders, 10%; Latinos, 19%; Native American/ Alaskan Native, 2%; and Whites, 39%. Youth-specific programs comprise over 35% of the overall funding, and funding directed toward women's HIV prevention programs comprise 30% of the total. In awarding funding, the AIDS Office relies on the priorities of the HIV prevention plan, the applications of agencies seeking funding, and when possible, the need already met by private and other governmental funds. The goal in supporting HIV prevention programs is to ensure some level of education and HIV prevention to all San Franciscans, with the bulk of funds targeted towards those most at risk for HIV infection.

San Francisco's prevention programs have made a significant impact in reducing the number of new infections. The Department of Public

Health's Consensus Report on HIV Prevalence and Incidence in San Francisco estimates that there will be 500 new HIV infections in 1997, a significant decline from previous estimates.

Of the 500 projected new infections this year, 336 are estimated to be among gay and bisexual men, including 53 who are also intravenous drug users and 64 who are under 30 years old. A total of 117 new infections are projected among female and heterosexual male intravenous drug users. The balance of the projections are: 15 heterosexual males, 30 women, 1 infant/child and 1 transfusion/blood disorder.

"Despite encouraging trends, estimates of HIV prevalence and incidence remain unacceptably high," the Consensus Report says. "Estimates ...underscore the need to maintain current, effective prevention programs. Moreover, to sustain behavior change over long periods of time and to keep pace with evolving technology, prevention efforts need to be repeated, updated, and presented through a variety of media and programs. Maintaining current resources is critical to prevent further transmission and avert the development of future 'waves' of HIV infection among new generations or persistently vulnerable populations."

The field of HIV prevention and health education is frequently misunderstood. Prevention isn't merely dissemination of brochures and condoms. Effective prevention requires an understanding of health education, behavioral psychology, sociology, culture and epidemiology. Prevention practitioners must understand human behavior, theories related to safe behavior and strategies for empowering individuals and communities to create change.

In prevention, health educators, street outreach workers, therapists, peer educators, and other prevention practitioners assist individuals and communities in their understanding and assessment of personal risk. Prevention educators do not prescribe standard interventions. While factual information and multiple environmentally and culturally appropriate alternatives to risk behaviors are necessary components of prevention efforts, these options by themselves do not necessarily lead to behavior change. An individual or community must personally assess their behaviors, weigh the consequences of their choices and apply learned skills if they choose to make necessary changes. Prevention is the adoption and maintenance of safe behavior. Prevention is not done to or for an individual or community. Prevention efforts enable individuals and communities to take action in their own behalf.

While new medical interventions toward preventing HIV are recognized as important new approaches to reducing HIV infection, we must

also recognize that the focus of primary prevention must remain on assisting people from becoming exposed to HIV. Despite advances in treatment that can dramatically reduce viral loads, extending life expectancy and improving quality of life, medicine should not be perceived as primary prevention. There is no evidence that HIV-positive people don't transmit the virus when viral load is undetectable.

The fact is that people within our communities are still becoming infected. We must continue to remain vigilant about assessing, supporting, refining, and implementing high impact behavioral risk reduction strategies and interventions which address the behavioral and psychosocial complexities of risk to reduce primary HIV infections.

The combined voices of prevention practitioners, the communities within which they work, and social scientific community have led us to important reassessments of the concept of "risk" in approaches to disease prevention. It is clear at this point in the epidemic that continued efforts to reassess behavioral risk reduction approaches to disease prevention (i.e. recognizing that psychosocial variables, social interactions, notions of identity, community and other social and environmental realities all impact individual behavioral choices) are critical to rethinking and refining our prevention efforts and achieving our public health goals of reducing new HIV infections. We still have much work to do in redefining behavioral risk to take into account such social and psychological complexities.

Clearly, however, we must not privilege medical interventions toward prevention at the expense of behavioral and psychosocial interventions. Rather we need a combination of these. In developing better prevention interventions and strategies which minimize barriers to harm and risk of primary HIV infection, we need to assist HIV prevention practitioners in their efforts to address the behavioral complexities of risk taking behaviors among clients. We must also foster cross-disciplinary and integrated efforts between substance abuse and mental health programs and HIV risk reduction interventions, and support practitioner, client-centered, and research efforts to comprehensively redefine "HIV risk".

Recommendations

1. The HIV Prevention Planning Council should be supported and enabled to remain responsive to the changing epidemic.

San Francisco is one of six cities that is directly funded by the federal Centers for Disease Control and Prevention to have an HIV Prevention Planning Council. According the CDC guidance, "HIV Prevention Community Planning is an on-going process by which state and local health departments share responsibilities for developing comprehensive HIV prevention plans with other state and local agencies, non-governmental organizations, and representatives of communities and groups at risk for HIV infection or already infected."

San Francisco's planning council was established in 1994 and currently consists of 37 members of the research, service, medical, activist, and public health communities. Its multicultural composition reflects the epidemic in San Francisco. One of the primary charges to the HIV Prevention Planning Council is to consider the epidemiological data, incorporate community values, and establish a mechanism for prioritizing populations to receive HIV prevention resources.

With a mission of reducing the number of new infections in San Francisco to zero, the HIV Prevention Planning Council recognizes the importance of targeting resources towards people at highest risk for contracting HIV. Rather than prioritize by demographic profile (risk group) the HIV Prevention Planning Council prioritizes according to risk behavior. In this paradigm shift, it is not *who* people are but what risk *behaviors* they engage in which directs the priority-setting process.

While recognizing that there are several cultural factors which influence where the epidemic is concentrated in the City, the HIV Prevention Planning Council intentionally prioritizes HIV prevention programs towards those individuals at highest behavioral risk within those cultural groups. This focus on risk behaviors and marriage of epidemiological data with community values represents a new direction in HIV prevention planning.

The programs currently funded through the San Francisco Department of Public Health reflect the first time the Community Planning priorities were used in funding decisions.

The HIV Prevention Planning Council developed guidelines for a one-time behavioral risk assessment to be conducted by every HIV prevention provider. This risk assessment requires HIV prevention providers to go beyond a simple counting of clients or hours in reporting on their work. The behavioral risk assessment allows agencies to determine whether the clients they are reaching are indeed engaging in high risk sexual or drug use activities. For example, if an agency provides health education sessions for women, are the women they're reaching those who engage in behaviors which put them at risk for HIV transmission? More information about clients' risk will help agencies target that risk and tailor programs to their particular client population.

This newly mandated assessment represents the first time community agencies have engaged in a coordinated standardized data collection effort. The results from the first year of the assessment will be available in early 1998, and will give us our first picture of the risk behaviors of the clients in San Francisco.

HIV prevention programs cannot be effective if the agencies conducting them are not effective. Each of the agencies funded by the AIDS Office and programs within the Department of Public Health had an agency-wide capacity assessment, with specific assistance plans developed for each agency. The individualized assistance plans are designed to help San Francisco agencies conduct the behavioral risk assessment, use the data, and develop responsive programs in well-functioning agencies.

A second priority of the HIV Prevention Planning Council is to ensure culturally competent HIV prevention programs, programs which are tailored, effective, and appropriate to the client population. Culturally competent programs are consistent with community norms and are easily accessible (in terms of language, setting, format, and message) by the intended clients. Currently the HIV Prevention Planning Council is developing a tool for evaluating the cultural competency of agencies providing HIV prevention programs. The tool was sent to 210 HIV prevention, care, and treatment providers for input and comment. Once it is finalized, this cultural competency tool, and its underlying principles, will be used in the determination of funding awards as well as program monitoring. HIV prevention programs must address the ethnic, sexual orientation, gender, economic, age, and other cultural characteristics if clients will be appropriately served.

In addition to the tasks described above, the HIV Prevention Planning Council has identified and prioritized the gaps in surveillance and intervention research; conducted an exhaustive research literature search;

set standards for prevention programs, and conducted a needs assessment and an inventory of HIV prevention resources.

Recommendations:

1. *The ongoing work of the HIV Prevention Planning Council should be supported, and it should be encouraged to maintain its responsiveness, flexibility, and links to the communities it serves.*

2. *The Planning Council will have results in 1998 on behavioral risk assessment findings, new cultural competency tools to be used in the awarding of new contracts and monitoring of ongoing programs, prioritization of intervention studies needed to address HIV prevention in San Francisco, and the revised priority-setting model. Other social service areas examine the outcomes of this process (priority-setting model, cultural competency tool, mandatory behavioral risk assessment process, and prioritization of research gaps) to assess their utility in non-HIV related fields.*

3. *Intervention research that has been identified and prioritized by the Planning Council should be adequately funded.*

2. HIV prevention must be better integrated with other social services.

HIV prevention must be seen as inextricably linked to the City's complete network of social services. A more holistic, integrated approach is needed for HIV prevention as demographic trends in the epidemic shift to persons with multiple social service needs.

Effective HIV prevention is often undermined by competing life priorities. It is difficult to maintain a commitment to safer behavior when issues such as substance abuse, immigration, housing, financial security, and mental well-being seem more immediate priorities.

Strengthening and integrating the City's social service system should be considered an important part of HIV prevention, and HIV prevention must be seen as part of the City's social service system. Strengthening City programs that address problems in housing, substance abuse, mental health, poverty, vocational education and criminal justice would help create an environment that discourages HIV transmission.

A substance abuse or mental health intervention may very well be effective HIV prevention – even if it does not include a specific HIV message.

The Department of Public Health has begun a major restructuring of the City's disease prevention, health promotion and health services. This has involved all divisions within the department and will also impact the organization of community-based services contracted by the department. An important outcome of this restructuring should be better integration of disease prevention and health promotion efforts, including those dealing with HIV, substance abuse, tuberculosis, sexually-transmitted diseases, women's health, and youth, maternal and children's health. Within this restructuring, HIV prevention efforts need to be amplified and continue to be a high priority for the department's resources.

Recommendations:

1. *The Mayor should establish with the Department of Public Health and other relevant City departments a multi-disciplinary task force to better integrate HIV prevention activities with other social services.*

2. *The Health Department should coordinate referral systems and sharing training materials between HIV prevention and other service agencies. Cross training, especially for community health outreach workers, should be undertaken.*

3. *The Department of Public Health's current reorganization plan is a positive step toward integration. Funding for HIV prevention must be provided at the same or higher level and not be diluted.*

3. Provide HIV-positive people with primary HIV prevention education and support.

The development of health education and community mobilization to prevent HIV infection over the past decade and a half has focused upon the general public, and upon those who were uninfected. Rarely have our efforts to prevent HIV transmission been focused on HIV positive people. Even among behavioral risk populations of injection drug users and gay and

bisexual men, HIV prevention efforts have not been formulated to help people living with HIV to reduce the opportunity of HIV transmission.

Over the most recent past, discussions among HIV prevention practitioners have centered upon how to better support gay and bisexual men who are HIV-negative to value and protect their lives. This discussion, emerging out of concern for HIV-negative gay and bisexual men who have begun to feel that HIV infection was inevitable, has led to a re-focusing of some prevention efforts, with targeted messages about hope, survival, and protecting one's life. Similarly, efforts focused upon injection drug users implicitly target people who haven't been infected, and lack explicit messages and support for HIV-positive individuals.

The challenges faced by sexually-active HIV-positive individuals has not been addressed as explicitly or as thoughtfully in new prevention approaches. HIV prevention programs should be directed to assist HIV-positive people to reduce their likelihood of transmitting the virus to non-infected people. People with HIV continue to play an important role in HIV prevention, and the City's prevention efforts must also embrace and empower them. While people with HIV have often been active in prevention efforts in the community as public speakers and educators, their role in HIV prevention within sexual relationships and encounters or needle use is seldom supported or addressed head-on.

Concerns regarding stigmatization, blame and discrimination against people with HIV have tempered or deferred a discussion of targeted HIV prevention in the past, and these concerns remain as HIV stigma, blame, fear, and discrimination exists in every part of our community still. This dilemma is most clearly felt in the gay and bisexual men's community, where sexual interactions between people of different serostatus occurs most frequently, due to high rates of sero-prevalence. Fear and avoidance of rejection, as well as fear and avoidance of rejecting someone based on HIV status has not only discouraged informed sex negotiation, but has sometimes facilitated riskier behavior because of incorrect assumptions of serostatus. There is increasing evidence of the importance of strengthening a sense of responsibility among HIV-positive individuals, and a sense of self protection among HIV-negative individuals, but without fostering separatism between these two groups.

New prevention efforts must incorporate both of these realities – by empowering people with HIV and decreasing HIV stigma – and must address the need to educate and support people living with HIV infection to avoid transmitting HIV. As one prevention activist said, "If there were only one condom left in San Francisco, I would give it to someone who is HIV-positive". This new approach is the necessary companion strategy of HIV-

negative targeted prevention efforts to impact the reduction of new infections, especially among gay men.

Recommendations:

1. *The HIV Prevention Plan should address strategies and target resources to assist HIV-positive people in adopting and maintaining safer behaviors and in avoiding infecting HIV-negative sexual and needle-sharing partners.*

2. *The Department of Public Health, and other entities providing primary care to people with HIV should encourage and fund the delivery and reinforcement of HIV and sexually-transmitted disease prevention information within primary care, mental health and substance abuse treatment settings – through Provider to Patient, disseminating HIV prevention materials within practice settings, etc.*

3. *Prevention practitioners, and community stakeholders should support and participate in community dialogues focused upon the goals of "shared responsibility" in HIV prevention between individuals of different serostatus, and the unique responsibilities of both HIV-negative and positive people to protect themselves and their partners.*

4. *HIV prevention workers should undertake new efforts to understand HIV stigma (irrational fear of HIV-positive people) in the context of sexuality and intimacy. This understanding needs to be incorporated into new HIV prevention efforts in order to empower individuals of either serostatus to make informed and responsible decisions regarding disclosure, negotiation, and sexual behavior. HIV prevention workers should make issues of disclosing serostatus an explicit focus of HIV prevention efforts.*

5. *There has been tremendous progress made in preventing HIV transmission from HIV-infected women to their newborn babies. In San Francisco, there have been 58 babies born to 56 HIV-positive women; none of the women who participated in the Bay Area Perinatal AIDS Center programs gave birth to an HIV-positive baby. Adequate funding must be provided to the Center to support effective multi-disciplinary effort of this kind.*

4. Although post exposure prophylaxis is one theoretical prevention tool, behavioral prevention must remain our highest priority.

Post exposure prophylaxis (PEP) is a new and experimental intervention that can augment present HIV prevention strategies. A person who believes that he or she may have been exposed to HIV through sexual or other contact can be prescribed combination drug therapy soon after exposure to attempt to prevent infection. Research is underway, including at San Francisco General Hospital and City Clinic, to determine the feasibility and behavioral impact of this treatment.

PEP has been touted by some in the media as a "morning after pill", leading to concerns that some people may increase risky behavior. Although medicines have been shown to be effective in preventing some non-sexual transmissions (such as mother-to-newborn), PEP has not been proven to be effective in sexual or needle-sharing transmissions. We should also not assume at present that people with HIV with undetectable viral loads cannot transmit the virus.

PEP provides the opportunity to reach high risk HIV-negative individuals to assist them in preventing exposure in the future as well as medications to potentially prevent infection from a recent exposure. But PEP, especially because its effectiveness is still unclear, is not an alternative to primary behavioral prevention strategies. Further, PEP should never be provided without concurrent counseling.

Recommendations:

1. *The public health department should work closely with the media to get the message out to the community that PEP is not a "morning after pill" and should not be used as an excuse to be exposed to HIV through unsafe sex or sharing of contaminated needles. Regular press briefings and editorial board meetings on this and other HIV issues should be undertaken by the Mayor, the Director of Public Health and other public officials.*

2. *The city should continue to support the effort to provide PEP to all people at risk for HIV who choose to use it, regardless of their ability to pay for the service. PEP should not be an alternative to primary prevention or be provided without concurrent behavioral counseling.*

Minority opinion: PEP should not be considered prevention. PEP is treatment in nature, while prevention programs should be considered behavioral change programs only.

5. HIV prevention practitioners must be current with changing information.

Currently, HIV antibody test counselors are required to have state certification and ongoing training requirements. Street outreach workers have outreach training certification. But such training certification and continuing education is not the standard throughout front-line and program development staff.

While many aspects of the epidemic and HIV prevention programs remain stable, much of the information and context for prevention is rapidly changing. New treatments leading to undetectable viral load may have an impact on perception of risk. New drug epidemics, especially poppers, crystal methamphetamines, and heroin, require current knowledge. New research findings showing psychosocial underpinnings to risk behavior need to be disseminated and incorporated into program design. New epidemiological data needs to be shared.

If we don't closely follow and address trends in the epidemic, we will always be playing "catch up" and will never get ahead of the spread of HIV.

Recommendations:

1. *All HIV prevention agencies should be required by contract to keep the skills of their front line and program development staff current by participating in a minimum number of training updates per year. These trainings could include sessions on: cultural competency, program evaluation and theory utilization, epidemiological trends, substance abuse (including the impact of poppers and crystal methamphetamines), the psychology of risk, impact of multiple loss, post-exposure prophylaxis, or other topics. The goal would be to keep programs relevant, to keep provider's skills sharp, and to require responsiveness to changes in populations.*

2. *Similar to grand rounds or required continuing education units, each agency should track its progress in maintaining the skills of its staff. The Department of Public Health's HIV Prevention Grand Rounds could be a vehicle for such training, although other trainings provided by consumer,*

research or other community trainers could satisfy this requirement. Health Department staff should be included in receiving ongoing training. This trainings could provide a forum for researchers and HIV prevention practitioners to share current information in a more timely way than through publications or newsletters.

6. Environmental barriers to preventing new infections must be overcome.

Harm reduction strategies are represented in a number of interventions implemented by community prevention programs – from needle exchange, to outreach/prevention case management to commercial sex workers, outreach at sex clubs, public sex, and needle-using sites. Programs employ condom distribution, media campaigns, peer and professional discussion groups, individual risk reduction counseling, and counseling, testing, referral, and partner notification. Harm reduction approaches encourage individuals to lower or reduce risk, and offer choices for people to do so. San Francisco has been a leader in reducing the number of new infections through hard reduction strategies, some structural, political and legal barriers remain which impede the full effectiveness of these programs.

While the San Francisco Police Department has demonstrated significant leadership in minimizing these barriers, HIV prevention outreach workers still experience incidents of harassment by some law enforcement officers at needle exchange sites, commercial sex areas, and massage parlors, which inhibits consistent accessibility and use of condoms and clean needles.

Recommendations:

1. *Model policies and practices which forbid the searching and seizure of condoms or syringes, or harassment of individuals for possession of these items should continue to be enforced and promulgated as consistently as possible in order to keep condoms and clean needles accessible at needle exchange sites, commercial sex areas and massage parlors. In addition, routine patrolling of massage parlors to enforce prostitution ordinances should not discourage or inhibit the use of condoms or other safer sex materials at these establishments.*
2. *Continue and strengthen community-based training of law enforcement officers who patrol public sex environments, commercial sex areas, and massage parlors to ensure that there is no harassment of individuals for their possession of condoms or clean needles.*

3. *The Mayor should convene the Chief of Police, Sheriff, District Attorney, the Director of Public Health, and concerned community interests to assess the environmental barriers to HIV prevention that can be overcome throughout the San Francisco criminal justice system, and determine methods to decrease barriers within the system. Forensic Services within the Department of Public Health should issue an assessment of existing barriers, and a plan that identifies appropriate ways for decreasing and eliminating any barriers to HIV prevention within the criminal justice system. This report should be made as a part of the Mayor's AIDS Leadership Forum and within regular progress reports.*

4. *Sex clubs have provided an opportunity for HIV prevention for those who may not be as open to other prevention interventions. Their operation should continue to be encouraged in promoting safer sex activities, providing condoms, and encouraging patrons to refrain from unsafe behavior.*

5. *In order to meet public health goals to eliminate HIV and Hepatitis C infections, clean syringes should be widely available. The Department of Public Health should encourage clean needle distribution at medical, substance abuse treatment sites, and at pharmacies throughout San Francisco. Providers should be funded and supported to distribute clean needles coupled with a mechanism for safe needle disposal. The public health goal of having a clean needle available for every injection should be the standard. Barriers to achieve that goal need to be overcome, including easier access to clean needle distribution.*

6. *The Mayor should review recommendations from the Prostitution Task Force and enact necessary recommendations that would facilitate HIV prevention efforts.*

7. *Substance abuse treatment on demand using harm reduction strategies (and not only traditional abstinence-based models) should be made available to any San Francisco resident. Continuing to use drugs should not be a barrier to substance abuse treatment that may reduce of HIV infection.*

8. *The Mayor should support the funding and development of the latest interventions which use harm reduction strategies and work with those at greatest risk for HIV.*

9. Condom distribution programs should be adequately funded. Both penile and Reality condoms, as well as information on usage and efficacy, should be readily available in bars, sex clubs, health centers, clinics and agencies.

7. Stronger collaboration is needed between HIV prevention practitioners and researchers.

With the rapidly changing nature of HIV illness, providers of HIV prevention programs must be informed about the effects these changes have on the populations to which they serve. For primary prevention of HIV among those uninfected, service providers need to remain informed about who is most at risk and what the particular behavioral and psychosocial needs of those individuals are so that scarce resources can address the issues most relevant to those populations. What might be an appropriate prevention strategy or intervention for one population may not be for another.

Similarly, service providers who work with people already infected with HIV need to know more about the ever changing circumstances that one may engage in high risk behavior and also to respond to the rapid changes and advances in drug therapies.

The knowledge about the experiences of the people served by the City's service providers are often not population-specific. While many prevention messages may be applicable across populations there are as many others that are not. A collaborative effort between researcher organizations who can make assessments of individual populations with service providers who can assist in the development of the research question is an efficient way of collecting information and feeding it back to the providers in a relatively short period of time.

In pilot programs in San Francisco, both groups are working with each other from questionnaire design through data analysis and then in the development of interventions based on the data collected. The researchers inform the providers what the specific populations are saying their needs are and the service providers can respond to those needs. At the same time, the service providers are then in a unique position to supply the researchers ongoing questions that arise out of their populations which can be used for further study.

Waiting long periods of time for research to inform practice is not necessary and with the rapid changes in the AIDS epidemic is even irresponsible.

Recommendations:

1. *The City should ensure funding for service providers to engage in research collaboration with either university based research institutions, or other agencies that specialize in HIV/AIDS prevention. Funding for service organizations/researcher collaboration should cover original formative and outcome evaluation as well as the process of technology transfer.*

2. *HIV prevention practitioners should be involved with developing and monitoring the behavioral and psychosocial prevention research agenda for the UCSF AIDS Research Institute, which includes a partnership with the City.*

3. *We recommend that researchers make greater efforts to disseminate the results of their work in the community, especially any research findings that could assist in designing prevention programs.*

8. Effective HIV prevention requires knowledge about sexuality among the populations at risk for infection.

Fifteen years of HIV prevention have demonstrated that having HIV information and negotiation skills often are not sufficient ingredients to guarantee that individuals will stay safe and avoid behaviors that could put them at risk for HIV infection. There is increasing evidence, emerging from both research and practice, of the pressing need for individuals at risk to acquire greater knowledge about the role that sexuality plays in their lives, and about the factors that might lead them to take unwanted risks in the heat of the moment.

Addressing this need requires that AIDS prevention workers question several assumptions of current HIV prevention efforts. The first is that all programs should exclusively focus on the topic of HIV *per se*. Instead, we need to expand our palate of topics to include analysis and self-reflection about sexual partners, lovers, desire, trust, intimacy, passion, love, serostatus, non verbal communication, self-image, disclosure, and power inequalities, among other topics. Rather than understanding these issues solely as "co-factors" of infection, we must realize that they play a central role in the decisions that people make about what kind of sex they have and with whom.

The goal of acquiring greater knowledge about sexuality and other related topics, in connection with HIV, requires a much stronger emphasis on fostering critical thinking as part of a process of empowerment.

Accomplishing this task requires expanding from the more commonly accepted didactic methods of prevention, in order to provide a greater emphasis on adult education and community organizing as tools of prevention. In other words, we need to shift the locus of prevention education from the providers of services to the communities at risk, so that it is people themselves who define and tailor prevention strategies to their needs through critical thinking and empowerment.

From a research perspective, what is needed is a greater inclusion of the social sciences in the conceptualization of HIV prevention interventions or, in other words, and expansion from the dominant discourse of the traditional behavioral sciences. This means that we learn, in the process of doing research, not only about behaviors and their causality, but also about sexual meanings, interpersonal relations, sexual cultural scripts and, in general, about the role that sex and sexuality play in people's lives.

Recommendations:

1. *The HIV Prevention plan should address strategies to promote thinking critically thinking among individuals at risk for HIV infection. Such strategies should establish ties between the larger topic of sexuality and HIV prevention, and provide AIDS prevention workers with tools to establish those links in the creation of their programs.*

2. *The emphasis on knowledge about sexuality calls for the fostering of efforts that "start where the people are" and that assist individuals in the creation of personalized strategies to stay safe. The Department of Public Health, and the Planning Council should encourage HIV prevention practitioners to learn the principles of community organizing and expand from the more common didactic models, to include models that foster empowerment.*

3. *HIV prevention workers should undertake new efforts to tie the topic of HIV transmission more explicitly with the broader topic of sexual meanings. It is crucial that HIV prevention practitioners engage with their target population to learn how individuals make decisions about sex and how HIV prevention can be integrated into such decisions.*

9. The School District's programs of condom availability and bilingual health education need to be fully funded.

The San Francisco Unified School District has implemented laudable policies to make condoms available at all high school sites since 1991. The district also adopted a health education curriculum, which includes family life and HIV prevention for all grades using age-appropriate health promotion concepts. These programs have had an important impact upon HIV prevention in the schools, yet have not always been implemented fully because the programs are grant-funded.

While the curricula is a required health course for all students, including students in bilingual and special education programs, there have been insufficient funds to develop bilingual materials, and training manuals. Given the high proportion of students and parents who use English as a second language or are monolingual, there is a need to fully support the implementation of these policies with additional resources.

Comprehensive health promotion which includes gender-appropriate and age-appropriate content regarding sexual orientation and sexuality will continue to be an important component of San Francisco's HIV prevention strategy and should be supported at a level to fully implement the policies.

Recommendations:

1. *Ensure the availability of condoms and other latex barriers at all high schools with adequate annual funding, and minimize environmental barriers to their availability.*

2. *Review current implementation of family life and HIV prevention curricula, and provide adequate support for instruction to special education and limited English speaking students, training for special education and bilingual teachers, and resource materials for limited English speaking parents.*

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Access to Therapy
Subcommittee Report

Introduction

Utilization of present day therapies for HIV infection is a complex, multi-faceted process. It requires a consistent doctor-patient relationship and extensive support and follow-up just to be sure that prescribed medications are used properly. Inadequate adherence to combination therapies regimens can quickly lead to a loss of their effectiveness due the development of viral mutations which confer resistance to the drugs which have been used. When this occurs, it has implications both for the patient and for the public health. On an individual level, treatment failure with one regimen typically creates some degree of cross-resistance to other unused therapies. Consequently, the patient quickly exhausts the utility of all available treatment. This in turn also has implications for the public health since the patient's resistant virus can likely be transmitted to others. This may make it possible for newly infected people to present with strains of virus which are already resistance to therapy.

Access to effective therapy may also be a primary public health issue from another perspective. When properly employed, today's best therapies are capable of reducing the amount of replicating virus in a majority of patients to undetectable or near undetectable levels. Although not yet supported by hard data, most scientists believe that widespread success in reaching such levels of viral suppression would almost certainly have a positive effect on the transmission of infection from successfully treated patients. Thus, effective treatment may well also be a potent tool of prevention, lowering the risk of transmission. Critics may rightly argue that this point is unproven, however logical. It may never be possible to ethical conduct a study to test this point, but there is little scientific reason to question its validity. However, with this potential benefit there also comes a potential problem. If people perceive themselves as less capable or incapable of transmission, might this encourage a greater degree of risky sexual behavior. And if so, what is the net effect on disease transmission between these two contradictory forces? If nothing else, this dilemma highlights the importance of maintaining our city's vigilant prevention efforts and warns us not to place all our eggs in one basket – in this case, treatment.

We must also remember that effective access to therapy begins with access to primary health care. Without it, and without the ongoing support and guidance required by today's therapy options, patients have little chance

of successfully managing HIV disease or making good use of therapy. In the public health setting, this means that patient should not be expected to receive primary HIV therapy through emergency room visits, but through a consistent program of care which follows the patient throughout the course of illness.

Recommendations

1. Access to Treatment

The new San Francisco model should build upon the treatment recommendations already made by the Department of Health and Human Services Federal Guidelines for the Use of Antiretroviral Therapy. These Guidelines spell out the drugs and related diagnostic methods required to effectively treat HIV disease.

The Federal Guidelines are meant only as a starting point for making individualized therapy decisions and are not intended to provide a rigid formula for treatment. Moreover, they will almost certainly change rapidly over time as new information and better drugs become available. Today, these Guidelines recommend the following forms of treatment whenever treatment is indicated:

- Initial therapy should include a three drug combination, typically employing one highly active protease inhibitor and two nucleoside analogues. For patients with advanced disease who might have exhausted the utility of many of the therapies approved earlier in the epidemic, an effective treatment regimen might require four or more drugs.

- Diagnostic support necessary for the proper use of such treatment should also be guaranteed.

- These recommendations are the same whether the patient is just beginning therapy or changing from a previous therapy which no longer effectively suppresses viral replication.

- Patients needing to switch from a currently failing treatment regimen should change at least two of the three drugs currently used, or ideally, all three.

- The goal of therapy is defined as achieving "undetectable" viral load on the best available viral assays, for as long as possible.

Recommendations:

1. *We recommend that it should be the policy of the City of San Francisco to make sure that its HIV-infected citizens have access to the full spectrum of treatment regimens described by the present and future versions of the Federal Guidelines for the Treatment of HIV Infection, as well as any community standards which might supplement the Federal Guidelines.*

2. *We recommend that it be the policy of the City of San Francisco to make sure that its HIV-infected citizens have access to whatever therapies are needed (within the limitations of FDA approval) to fill the gap when existing therapies fail. Patients should not be rigidly limited to a choice of three drugs if additional agents seem necessary to achieve the goals of treatment described in the Federal Guidelines.*

3. *Over time, the Federal Guidelines may be revised to require either more or fewer drugs as the basis for therapy. Whatever those future recommendations may be, we recommend that The City make sure they are rapidly made available to its HIV infected citizens. To achieve this, we recommend that the City of San Francisco empower an oversight panel that could quickly review new advances in therapy for inclusion in the City formulary, as well as the formularies used by third-party payers and the AIDS Drug Assistance Program.*

2. Access to Diagnostic Support

The Federal Guidelines for the Use of Antiretroviral Therapy state that the use of viral load testing and CD4+ cell testing are essential for the proper use of combination therapy. Use of treatment without the diagnostic testing greatly increases the risk of using treatment ineffectively, therefore causing the development of multi-drug resistant strains of HIV and damaging the patient's ability to control the infection. The San Francisco Model should therefore guaranty that every HIV positive person have access not only to the treatments described elsewhere in this report, but also to the diagnostic tests necessary to make effective use of the treatments.

Viral load testing (also known commercially as the Roche Amplicor or Q-PCR assay and the Chiron b-DNA assay) is required for three purposes:

- Initially upon HIV diagnosis to determine the need for therapy.

- Prior to the initiation of therapy to establish baselines for evaluating the effectiveness of treatment. The Federal Guidelines suggest that people should be tested twice within a short period (a month or less) to establish the baseline for treatment. Two test results, performed at the same laboratory, are required to minimize the chance of error in any single test.

- Periodically (approximately 3-4 times annually) throughout the use of treatment to evaluate continuing effectiveness and to watch for early evidence of treatment failure. When a single test result indicates the possibility of treatment failure, that test should be repeated as quickly as possible to verify the results.

CD4+ cell testing has long been a staple of treating HIV disease. It's most important uses are (1) in the staging of the disease (as a measure of cumulative damage to the immune system), and (2) for determining the risk of opportunistic infections. Existing guidelines for the use of this test are unchanged and call for patients to have access to CD4+ cell testing approximately 4 times annually.

Recommendations:

1. *We recommend that the City of San Francisco guarantee its HIV-infected citizens access to at least the minimal numbers of diagnostic viral load and CD4+ cell assays and any future diagnostic tests recommended by the Federal Guidelines. Whenever possible, we encourage the City to work closely with manufacturers and suppliers to take advantage of any special assistance programs offered.*

3. When Should Therapy Be Offered, and to Whom

The common theme of current HIV management is summarized in the phrase "hit it hard and hit early." This is interpreted by many as meaning that all people should be treated immediately upon evidence of HIV infection. The actual recommendations of the Federal Guidelines for the Use of Antiretroviral Therapy are somewhat more complex. If we knew that therapy could be used successfully for the lifetime of the typical patient, then certainly the earliest possible treatment would make sense. However, we still lack a great deal of information about the long term effects of therapy and how very early treatment affects future treatment options. Some physicians worry that the cumulative long-term side effects of HIV therapies may outweigh their usefulness if the drugs are used too early in the course of

disease. Others worry that using drugs too early may cause the patient to use up all available treatment options relatively early in the course of disease and leave few if any potent options for the more advanced stages of illness. To the contrary, others feel that very early use of the most potent therapy options may be the best way to slow or stop all progress of the disease. Until true long-term studies on this question are completed, there may not be a single correct answer to the question of when to start therapy. Individual judgment by patient and physician will continue to play a role in answering this question on an individual basis.

The Federal Guidelines for the Use of Antiretroviral Therapy recommend that treatment be offered to all HIV-infected people with CD4+ counts below 500. For those with counts above 500, additional factors, particularly the patient's viral load, must also be taken in to account. For people with CD4+ counts above 500 who have a relatively high viral load (as defined by the Guidelines), treatment should be offered. For people with CD4+ counts above 500 who have a relatively low viral load (as defined by the Guidelines), the presently recommended course of action is to continue observation with viral load and CD4+ cell tests, but not necessarily to start therapy. As a second and still valid choice, the Guidelines suggest that patients with these characteristics might be offered treatment instead. The decision to treat or not treat in this case is still a judgment call, one that should be made after careful discussion between patient and physicians about the possible risks and benefits of treatment.

The current state of knowledge includes this uncertainty about when to start therapy and acknowledges that there are good arguments for either point of view – to treat or not to treat certain patient populations. Therefore, we recommend that city policy not attempt to impose its own medical judgment into these matters by restricting access to treatment to people above or below any particular threshold.

Recommendation:

1. *We recommend that the offer of treatment be extended to all patients who seek it, without regard to their current stage of disease, after consultation with their physicians. The city's position should be neither to encourage nor discourage treatment in the earliest stages of disease, but rather to recognize that this is a medical question which should best be left in the hands of the patient and his or her physician. This recommendation, however, underscores the importance of the recommendations in the Section regarding Access to Information. Physicians who seek to guide this decision with their patients must be as fully informed as possible about the potential risks and benefits of very early intervention.*

Acute Infection

A similar principle should guide the use of therapy for people who present in the "acute infection" stage. This is defined as people with initial flu-like symptoms subsequent to an HIV exposure and who test positive on PCR. The media has popularizes a series of small clinical trials being conducted with the patient population. In the trials, patients are put on aggressive triple combination therapy as soon as infection is confirmed. It had been hoped that such immediate action might lead to complete eradication of HIV infection, but so far, this has not been the case. The question remains whether such immediate treatment results in longer life or symptom free survival for the patient. No answer yet exists to this question, although there is evidence that patients respond well to the treatment in terms of lab markers. The question for physicians is whether or not to attempt treating people who present in this fashion. Effective arguments have been raised both for and against treatment for acute infection.

Our recommendation here is the same as for other forms of early intervention. The decision should be left in the hands of the patient and the physician, and the patient should be granted access to therapy if that is the option chosen. Such a policy encourages the City, and more importantly, managed health care operating in the city, to refrain from making medical decisions in matters of uncertainty, and leaving those questions to the physician and the patient.

Special Situations

The use of complex antiretroviral regimens in certain situations affected by homelessness, unemployment, poverty, or drug addiction, has been hotly debated by physicians, researchers, ethicists, and patients. Some argue that unless the patient is in a reasonable position to adhere to the complexity of a treatment regimen, the physician may do more harm than good by providing treatment. Those who take this position point out that the likely misuse of treatment will quickly lead drug resistance and failure. This in turn will almost certainly damage the patient's chances for effective therapy at a later date, and may create an opportunity for the transmission of multi-drug resistant virus. In contrast, others argue that physicians should not attempt to make judgments about patients' ability to adhere, nor should they ever deny treatment to a patient who needs it. Instead, physicians should be encouraged to learn as much as possible about how to improve adherence to therapy and the City should encourage the

development of studies and programs about adherence by existing resources, such as the Center for AIDS Prevention Studies, the AIDS Education and Training Centers, or other community organizations.

The ethics and needs of such situations varies enormously on a case to case basis, something the City of San Francisco cannot do in a policy statement.

Recommendation:

2. *We recommend that it shall be the policy of The City of San Francisco to always do its best to provide services on demand to be sure that the underlying problems of homelessness, unemployment, poverty or drug addiction are addressed along with the need for HIV therapy. However, whether or not this goal can be achieved, the City should not interfere in the right of patient or physician to access therapy, regardless of the underlying conditions.*

Post Exposure Prophylaxis

Clinical trials are currently testing whether or not immediate use of antiretroviral treatment following exposure to HIV might reduce or eliminate the risk of productive infection. The effectiveness of therapy of this type has been demonstrated for health care workers exposed through accidental needle sticks or fluid exposures. There is as yet no evidence that post exposure prophylaxis works similarly for sexual exposure.

Recommendations:

3. *We recommend that it be the policy of the City of San Francisco to guaranty access to post-exposure therapy for health care workers exposed in their work.*

4. *We recommend that it be the policy of the City of San Francisco to guaranty access to post-exposure counseling for those who seek it, and whenever desired, access to clinical trials testing the feasibility of post-exposure prophylaxis.*

4. Access to Information

While San Francisco offers many of the nation's most experienced HIV physicians, not every HIV-infected person has his or her choice of physician, nor are all physicians equally specialized in their knowledge of treating HIV disease. This is particularly true in the managed care environment and in the public health setting. Even in San Francisco, individual physicians sometimes attempt to treat HIV infection without adequate knowledge of the latest information. Studies have shown that a physicians experience in treating HIV disease can play a significant role in patient survival time. When physicians lack information about important therapy options, those options are effectively denied to their patients. Therefore, physician education and access to information can be a very real factor affecting patient access to therapy.

Recommendations:

We recommend the following to more effectively guarantee the most uniform possible approach to HIV care in San Francisco:

1. *To the extent possible, all physicians treating HIV-positive people should be confidentially identified within a single city-appointed agency or organization and listed in a database to facilitate the distribution of information and resources regarding the treatment of HIV infection.*

2. *Every physician known to be treating HIV infected persons should receive (at least annually):*

    a) *copies of the current version of the Federal Guidelines for the Use of Antiretroviral Therapy; when updates are published, they should immediately be distributed to the physician database*

    b) *a complete description of all available HIV therapies, their proper uses, and their possible interactions with other commonly used medications*

    c) *a listing of available resources for referral or consultation with specialized centers such as San Francisco General Hospital and the University of California, San Francisco Medical Center.*

    d) *a listing of available community resources which provide additional information, support, or other resources for people with HIV disease.*

e) a list of respected newsletters and publications which provide frequently updated information on AIDS treatment and research; ideally, such publications should be routinely delivered to physicians and made available to their patients.

3. The City of San Francisco should appoint or create a single agency, phone number, or office empowered to act as an ombudsman for patients seeking access to sources and reimbursement for treatment.

5. Drug Sources and Reimbursement

Due to the success of past programs and effective long-term planning, people with HIV in San Francisco today already have a high level of access to therapy. This is not to say, however, that all problems are solved. When an HIV-positive person in San Francisco feels he or she has no access to therapy, it is often more due to a lack of information than a lack of available resources. The result for the patient, however, is the same. The issues surrounding drug access differ widely depending on the type or lack of medical coverage held by the patient.

Private Insurance and Managed Health Care

People with high-end private insurance plans have typically reported few problems in accessing the new combination therapies. Where problems occurred, it was usually during the early months of a new therapy's availability, before the plan administration had enough information about the drug or drugs. The most common problem for people with private insurance, therefore, is making sure that their carriers act quickly on new information as soon as it becomes available from the FDA approval process.

Recommendation:

1. We recommend that a uniform process be established to notify major insurance plan administrators regarding the availability and role of new therapies.

This issue also plays a role in the managed health care environment, but here, additional factors sometimes may cause limitations on access to therapy. In some instances, managed health care corporations have been slow to incorporate new therapeutic agents in their formularies. This is sometimes due to procedural matters, lack of information, or concern about

long-term cost implications. Cost concerns are meaningful only when there is major shift in therapy models, such as the change from two-drug combinations to three-drug combinations. Now that we are well established in the three-drug era, the availability of a new therapy generally represents a replacement for a similar item already being covered, rather than a new, additional expense. Therefore, it has minimal effect on costs.

Recommendation:

2. *We recommend that, like high-end private insurance, managed care plan administrators should be notified in some uniform way regarding the availability and role of therapies.*

Medicaid

In California, Medicaid has generally been quick to respond to the availability of new therapies, perhaps recognizing that better treatment ultimately lowers the cost of health care. The principle limitation of Medicaid is that it's current formularies require people to be functionally disabled before they qualify for coverage. In this regards, this makes Medicaid practice seriously inconsistent with the new Federal Guidelines, which recommend that treatment begin long before functional disability.

Recommendation:

3. *We recommend that the City aggressively support efforts to expand Medicaid to consistently support access to treatment in all situations currently recommended by the Federal Guidelines.*

AIDS Drug Assistance Program

The state/federal AIDS Drug Assistance Program (ADAP) was created to close a gap, to provide drug access for people who fell below certain specified income levels and were uninsured or underinsured. Funds for this program come both from the federal and state governments. There are severe limitations to this program in many states, but fortunately, the California program ranks among the better implementations. Still, California patients receiving drug through ADAP have often experienced delays in accessing important new therapies. These delays have been addressed on a case-by-case basis by local advocates who met with the State ADAP director.

In some states, there has been an apparently willful tug-of-war between ADAP programs and the manufacturer-sponsored patient assistance programs. In these instances, ADAP has been accused of delaying coverage of new drugs to force patients to demand access through drug company patient assistance programs. This in turn has caused some manufacturers to deny access to patients in a given state until the local ADAP program agrees to carry its part of the burden. Some companies have also been accused of holding ADAPs hostage by threatening to close their Patient Assistance Programs before the State ADAP is financially able or willing to cover their drug. Some states simply do not have the money, or will not allocate the money, needed to resolve these issues. None of this is acceptable as it makes the patients' most pressing medical needs little more than a pawn in the contest between public and private interests.

One key issue for people receiving drug coverage in this fashion in California is the speed with which new drugs are integrated into the formulary. California is currently undergoing a change to a centralized ADAP system which is designed to produce more uniform coverage, but it is unclear how this will affect the speed with which new drugs are made available.

Manufacturers' Patient Assistance Programs

As each new drug is approved, its manufacturer establishes a formal "patient assistance program" designed to make sure that no one is ultimately denied access to the drug for lack of ability to pay. While such descriptions make these programs sound expansive, they tend to be limited and sometimes difficult to access. Each company establishes its own income threshold and applies it uniformly throughout the country. This typically has an adverse impact on cities like San Francisco, where the cost of living is substantially higher than many other places. These programs also often run into conflict with ADAP, as each program is hoping that the other will cover the largest possible segment of the needy population.

In their favor, one advantage of these programs is that they tend to be quick in covering a new drug, since it is in the manufacturers' own interest to hasten the use of its drug.

Recommendation:

4. *We recommend that a particular City office or agency be authorized to act in the patient's interest in discussion with manufacturers about these*

programs and their relationship to other programs affecting San Francisco citizens.

Public Health Access

Patients receiving primary medical care through the San Francisco Public Health system should be guaranteed equitable access to new therapies and to the same standards of therapy as any other citizen, regardless of insurance, Medicaid, special programs, or personal wealth. Due to the high quality of past efforts, San Francisco currently has an excellent reputation in this regard. One of the principle issues facing people in this system however, is a lack of information about available resources. Resources for the uninsured are spread across many agencies and many possible programs. Navigating through the system isn't always as easy as it should be.

Today, much of this type of referral work is done informally by a collection of AIDS agencies and even by phone banks set up by pharmaceutical companies. But the sicker a patient is, the more needy or less informed, the more difficult it may be to find the ideal connection within this system to get what is needed.

Recommendation:

5. *We recommend that the City empower a single agency or office to take responsibility for directing patients to available programs whenever their current point of health care access is unable to locate or acquire a needed therapy. This agency or office should be staffed by people who are fully familiar with all of the programs and services available, both privately and publicly. Ideally, this can be accomplished by providing additional support to an agency already doing this work, rather an creating a new agency or office.*

Summary Recommendations:

6. *We recommend that the City, perhaps working through San Francisco General Hospital, offer periodic educational updates (with CME credit) about the state of the art in HIV treatment to appropriate personal working for private insurance agencies, managed care companies, the State ADAP office, and other personnel in the Public Health Department.*

7. *We urge the City of San Francisco to use its considerable presence and bargaining power to exert whatever influence possible on manufacturers to*

price their products and diagnostic services responsibly to minimize the financial burdens on the City and its citizens.

Subcommittee Members

Martin Delaney, M.P.A., *Chair*
Founding Director, Project Inform
Anne Donnelly
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Bay Area Youth Positives

Adherence to New Treatments Subcommittee Report

Introduction

In late 1995, the first of the new protease-inhibitor antiretroviral drugs was made available for persons infected with HIV. In combination with reverse transcriptase inhibitors, protease inhibitors produced unprecedented improvements in CD4 cell count, viral load, morbidity and mortality. Since their introduction, we have seen a dramatic reduction in deaths due to AIDS both nationally and here at home.

In San Francisco, the number of deaths due to AIDS has decreased from 1856 in 1992 to 854 in 1996. Because of improved longevity for people with HIV, the number of people living with AIDS in San Francisco has increased substantially. While some of the decline in deaths may be due to reductions in new infections, many attribute the decline in deaths to the introduction of life-prolonging combination antiretroviral therapy.

The decline in deaths is not equal with respect to risk group, gender or ethnicity. The greatest decline is seen among men who have sex with men, and the least is seen among heterosexual men and women. From the perspective of ethnicity, the greatest decline is seen among whites and the least among African Americans. While there are multiple reasons for these differences, one certainly involves differences among the groups in the extent to which there is awareness of an access to the new antiretroviral therapies.

Accompanying this advance in therapy was a recognition that strict adherence to these multi-drug regimens is essential to obtain the full benefits of therapy, maintain suppression of viral replication and prevent the development of resistance. Notwithstanding, recently published treatment guidelines emphasize adherence by stating: "Even short term nonadherence to an aggressive therapy may result in rapid virus repopulation in lymph nodes." *(Carpenter, et al, 1997)*

A problem emerges here because the combination therapies that are now being prescribed have exceedingly strict schedules with detailed directions regarding timing of doses in conjunction with eating, fat content of meals, and fluid intake. Without debate, these are the most complex regimens that have ever been prescribed for continuous and open-ended treatment of a large patient population.

We considered many approaches to address the problem of adherence in the context of protease inhibitors. The challenge is to help patients maximally benefit from these remarkable new medications. We agreed that we must also look at behavioral changes and readiness to change – not just in our patients, but in ourselves as well if we are to succeed in prolonging lives. Adherence to any medical or health regimen is the result of a dynamic process of human behavior. Simply put, the relationships between clinicians and patients, and between medical institutions and the communities in which they are located all influence the health outcomes of a community. Adherence is not just a patient issue, but a system issue. The health system must be constructed to facilitate, rather than undermine, adherence.

Our deliberations considered many elements: drug availability, drug resistance, factors leading to non-adherence, research data on adherence, concerns regarding the development and transmission of resistant virus, and the complexity of issues surrounding the treatment of people with HIV who are homeless, mentally ill, or substance users. We were challenged to explore the dynamics of the relationship between the health care system and a patient in order to understand and ultimately to influence human behavior in a social environment.

The Problem

The challenges associated with adhering to combination therapies for persons with HIV/AIDS are unprecedented. Given all that we currently know from research on adherence, many of the challenges associated with adherence to any medical regimen is present in anti-HIV therapy:

- Anti-HIV treatments can be extremely complex, and often involve taking up to 30 pills a day. These doses must be taken at precise intervals (e.g., every 8 hours) and frequently involve special dosing instructions such as: take with meals, take on an empty stomach, maintain a low fat diet, take with high fat meal, keep medication refrigerated, etc.

- Some drugs cause extremely unpleasant side effects. For persons who are in an asymptomatic stage of HIV infection, these harsh side effects can be more unpleasant than HIV disease itself.

- Avoiding and monitoring drug interactions is difficult.

- Unlike treatment for many other diseases, therapy to combat HIV is life long. Research shows that longer treatments are associated with lower adherence rates among all patient groups.

- How long these new combination treatments will be effective for anyone is unknown. Because it is believed HIV can "break through," or manage to circumvent current anti-HIV drugs, patients could be involved in extremely complex, long-term medical regimens that will, ultimately, fail them.

While lifetime adherence to triple combination antiretroviral therapy is particularly challenging, the importance of medication adherence for HIV care existed before protease inhibitors. Prolonged adherence to preventive therapy for opportunistic infections and tuberculosis has a similar impact on morbidity and mortality and should not be forgotten in our current enthusiasm for protease inhibitors. Adherence to other care plans including mental health support, drug treatment and alternative therapies must be addressed on an individualized basis in combination with antiretroviral therapy.

There is reason to believe that resistance could eventually develop for everyone on combination therapy, since no single combination has yet proven to eradicate HIV. However, the hope borne from combination therapy still remains from the evidence that these new drugs have bought many people years of increased life expectancy, allowing more time for further development of effective treatments for HIV disease. We must assist people in meeting these unprecedented challenges in adhering to their treatment plan.

The decision to embark on combination antiretroviral therapy is a complex interaction between patient and health care provider. Once this decision is made, additional assistance will be required for many individuals. The level of assistance will vary dramatically between individuals. Some may need a little instruction and guidance, while others may require substantial assistance to stabilize housing, mental health or drug use patterns before starting protease inhibitor therapy. Others may be so gravely disabled that meeting basic life needs and delivering preventive therapy for opportunistic infections may be all that is possible.

In addition to those individuals who choose not to take protease inhibitors, many people find that protease inhibitors fail to continue working for them after a time. These individuals, undoubtedly, will require professional assistance in coping with this difficult situation. It is critical that we as a community do not place the blame on these individuals for "failing" therapy. More accurately, the therapy has failed these individuals,

and we must insure the development of individualized treatment plans to maximize each person's heath potential.

The Obstacles

The unprecedented attention given to adherence by clinicians, researchers and the pharmaceutical industry in the last year, reflected in the plethora of conferences and workshops on the topic, provide a strong indication of the magnitude of the problem. Two studies with a total of over 200 patients on combination therapy indicate that at least 10% of patients on protease inhibitors miss a dose each day and that at least 20% miss a dose every two days. Both of these studies include patients with a wide variety of backgrounds, and include many patients seen at San Francisco General Hospital. As noted before, while the level of adherence needed to prevent viral replication is not known, any patient who skips a dose each day is at risk for viral breakthrough.

It is impossible to accurately predict someone's ability to adhere to therapy based on their sociodemographic characteristics, presence of a mental health disorder or drug use behavior. Falsely assuming that a street or shelter dweller is incapable of adhering to complicated therapy is ethically dangerous and would deny lifesaving therapy solely based on membership in a group such as the homeless. Given the difficulty predicting who will need the most assistance in advance of starting therapy, successful programs will require a broad based and individualized approach to improving adherence. The goal is to assist people in adhering to the most beneficial care plan possible; one that maintains health and personal choice and control.

We must not blame individuals for treatment problems or withhold therapy on unfounded assumption that someone may not be able to adhere. It is clearly more important to better understand and implement supports that allow people to take their medications effectively.

It is important to note that when treatment fails to achieve reductions in viral load, or when initial decreases in viral load give way to increases, there are at least several potential reasons. One reason is that the individual may not be responding due to a "host factor"; that is an individual reason adversely affecting the pharmacokinetics of the drug. For example: a patient may have a gastrointestinal or another disorder present in advanced HIV disease that interferes with absorption of anti-HIV medications. A second reason is that the patient may have already had an existing resistance to the drug or developed resistance to the drug(s) prescribed. A third reason, particularly relevant, is that the patient may have difficulty

adhering to the regimen. Unfortunately, the science of adherence has not caught up with the practice, so we cannot predict how closely individuals must follow their treatment schedules to realize benefits and avoid resistance.

Adherence to HIV medical care is particularly challenging for the urban poor. The urban poor includes people who are homeless, intermittently homeless, or who are marginally housed in single room occupancy hotels. Eighty-percent of people living in single room occupancy hotels report being homeless, either on the street or in a shelter in the past. In San Francisco, 8.5 % of the homeless and marginally housed population is infected with HIV. This represents an estimate of over one thousand homeless San Franciscans with HIV.

A critical step in addressing adherence issues for the homeless and marginally housed is meeting basic needs such as food, shelter and clothing. These obstacles raise questions about the ability of the homeless and marginally housed to adhere to complicated medical therapies. Untreated substance abuse and mental health disorders must also be addressed in this population. Thus, from the perspective of the urban poor, adherence is more system-related than patient-related.

Poor adherence to tuberculosis therapy in New York in the 1980s was often blamed on the patients, but adherence improved and tuberculosis case rates fell when the health care system was adapted to meet the unique needs of the indigent. The directly-observed therapy program at Harlem Hospital recently reported a 91% adherence rate when on-site and home-visit supervised therapy was made available to TB patients *(El-Sadr, Menard, & Barthaud, 1996).* This new, comprehensive program uses a surrogate family model, providing daily meals, transportation tokens, toiletries and clothing in an atmosphere that promotes a "sense of family" among staff and patients. Provision of effective medical care requires us to consider organizational, as well as individual, barriers to adherence.

Housing is the first step in improving adherence. Financial assistance, money management programs, and HIV directed housing often are not available to asymptomatic individuals for whom antiretroviral therapy is most effective. Flexible appointment scheduling, convenient clinic locations, and perhaps transportation to clinic and pharmacy would also facilitate adherence. The system must be organized in a way that makes it possible for the patient to adhere.

Secondly, homeless and unstably housed patients do not all experience the same barriers to adherence. There is a dramatic spectrum of functional

capacity in the homeless and marginally-housed community, as there is in the general community with HIV. Many people adhere to complicated 20 pill-a-day regimens flawlessly. Others find it impossible to add once-a-day pneumocystis pneumonia prophylaxis onto the daily challenge of securing food and shelter.

There are broadly overlapping clusters of people with HIV in San Francisco with respect to adherence. There is the cluster of people who have exceptional adherence to triple combination antiretroviral therapy and need little assistance. This cluster includes people who have stable housing and employment, but also includes many single room occupancy hotel dwellers and even some shelter and street dwellers.

There is a second cluster of people who have greater difficulty with adherence who are not optimally benefiting from antiretroviral therapy. These people are at the greatest risk of developing resistance to current therapies, however, with more intensive support, they may be able to realize the full benefits of viral suppression provided by modern antiretroviral therapy.

There is a third cluster of people who generally adhere well, but given the long-term nature of this medication, find themselves needing intermittent support.

And finally there is a fourth cluster of people who are gravely disabled with mental illness or substance use disorders for whom successful adherence to triple combination antiretroviral therapy is unlikely with anything short of a highly structured institutionalized living environment. For these people, the provision of basic life needs and the prevention of opportunistic infections, screening for Hepatitis C, and tuberculosis is a challenging and important first priority.

Ultimately we cannot forget, in our enthusiasm for antiretroviral therapy, that assistance with basic life needs and the provision of simple, effective and inexpensive therapy to prevent pneumocystis pneumonia and tuberculosis continue to be the first priority.

Adherence problems are not limited to those who are homeless. Many individuals with resources experience difficulty adhering to complex regimens. Decisions regarding initiation or maintenance therapy must take into consideration personal choice when seeking health care provider guidance. For some, a social setting or atmosphere of social acceptance can encourage adherence. These clients may need assistance to design their own

personal plan for health maintenance which may include prescribed medications or alternative therapies.

Some individuals feel overwhelmed by the requirements necessary for adhering to triple combination therapy. Individuals who work long hours away from home must remember to bring all the medication required for the day. Medication storage, dosage timing, appropriate meals and side effects are all part of their daily routine. Some individuals may require privacy to take their medications and therefore have to create a different daily schedule. Support may be required in the form of simple drug availability in a community venue. It is also important to emphasize adherence to prophylaxis strategies for those clients who falsely believe prophylaxis is no longer necessary once one is on "the cocktail".

It is important to say, that the sick and the dying must not be forgotten in our new hopefulness. These individuals need and deserve community support and services that specialize in the care of the terminally ill. For reasons related to lifestyle, quality of life, or personal philosophy, deferring therapy may be the best choice until the client feels fully ready to assume the responsibility involved.

Recommendations

1. Action Point Centers

How should these new therapies be delivered? Our goal is to provide the support and strategies to make an effective level of adherence possible.

Recommendation:

1. *We propose two, strategically located telephone and drop-in centers, called "Action Points" designed to support client adherence, lifestyle and readiness.*

Action Point Centers will provide services to people having problems with adherence to combination therapy and who are currently homeless and marginally housed. Those services include adherence tools and adherence counseling for both combination therapy and prophylaxis, counseling on developing and maintaining a health management strategy based on the harm reduction model. These centers would publish a catalogue of available educational and assistive tools for adherence including things like: timers, watches, pill containers, etc.

Services for the homeless that *must* be included at the Action Points are: counseling on adherence to *any* prescribed medical-pharmacological treatment, directly observed therapy (for TB, HIV) medication dispensing, food, prevention services for HIV-positive and HIV-negative people, referrals to other community-based partner agencies, showers and voice mail boxes.

By using store fronts for the centers, a wider audience of need can be addressed. The concomitant problem of insufficient affordable housing and increasing health challenges faced by homeless people can be more competently addressed in the centers we are proposing. Any homeless person will be welcome at the center, regardless of HIV status.

Because physicians and primary care providers do not have all of the tools or time to access multiple supportive interventions, meaningful assistance to San Franciscans living with HIV will require a multidisciplinary team approach, bringing together physicians, nurses, community health outreach workers, treatment advocates and social workers as the critical partners in individualized plan of care.

In addition to assisting the homeless and marginally housed population, Action Point centers would also provide training in adherence counseling and interventions for those serving HIV-positive people with their health care needs. By training community-based organizations, health care providers, outreach workers and others serving HIV-positive individuals with treatment and health care needs, the Action Point centers would help to ensure that people get appropriate adherence support through the mechanisms they currently use to access information. The web site and catalogue of adherence assistance tools would be available for use by community-based organizations and HIV-positive individuals.

Two ideal locations for these Action Points include the Civic Center area and near the Haight Ashbury Clinic. Since these programs may directly impact the HIV infected community ability to survive, we must formally evaluate the benefits of facilitating adherence. Given the urgency of the situation, we are proceeding with the Action Point intervention recommendation. While the interventions are underway, it is essential that we conduct evaluations so that valuable resources and efforts are devoted to those strategies that prove most successful.

2. Advocacy

There is much advocacy work to be done. Many of the problems that people experience trying to adhere to treatment have to do with the drugs themselves. The drugs currently on the market are expensive, making it difficult for many individuals to access all the medications they need. Currently available drugs require strict scheduling, multiple daily doses, and maintaining nutritional requirements in order to get optimum efficacy suppressing HIV. The drugs have an array of possible side effects ranging from bothersome to life-threatening. They also have multiple interactions with other necessary drugs. For example: in combination with protease inhibitors, Rifampin, a commonly prescribed drug for TB treatment, can result in a drastic reduction in blood levels of protease inhibitors; a simple anti-depressant can cause toxic levels of protease inhibitors. In addition, the drugs exhibit cross resistance to other drugs in the same class.

When considered as a whole, it is clear that we need to advocate for better anti-HIV drugs if we expect more people to be able to reap and sustain the benefits of treatment. Less expensive drugs that are easier to take will make a substantial difference in people's ability to adhere to a treatment regimen.

Recommendations:

1. *We urge the city of San Francisco to use its influence as a noted leader in health policy to advocate with the Federal government, particularly the National Institutes of Health, and the pharmaceutical industry to initiate and continue the research necessary to find better and less expensive anti-HIV therapies.*

2. *We urge the City of San Francisco to advocate with industry to strengthen research and collaborative efforts to develop different mechanisms of drug delivery aimed at making HIV treatment more sustainable for more individuals.*

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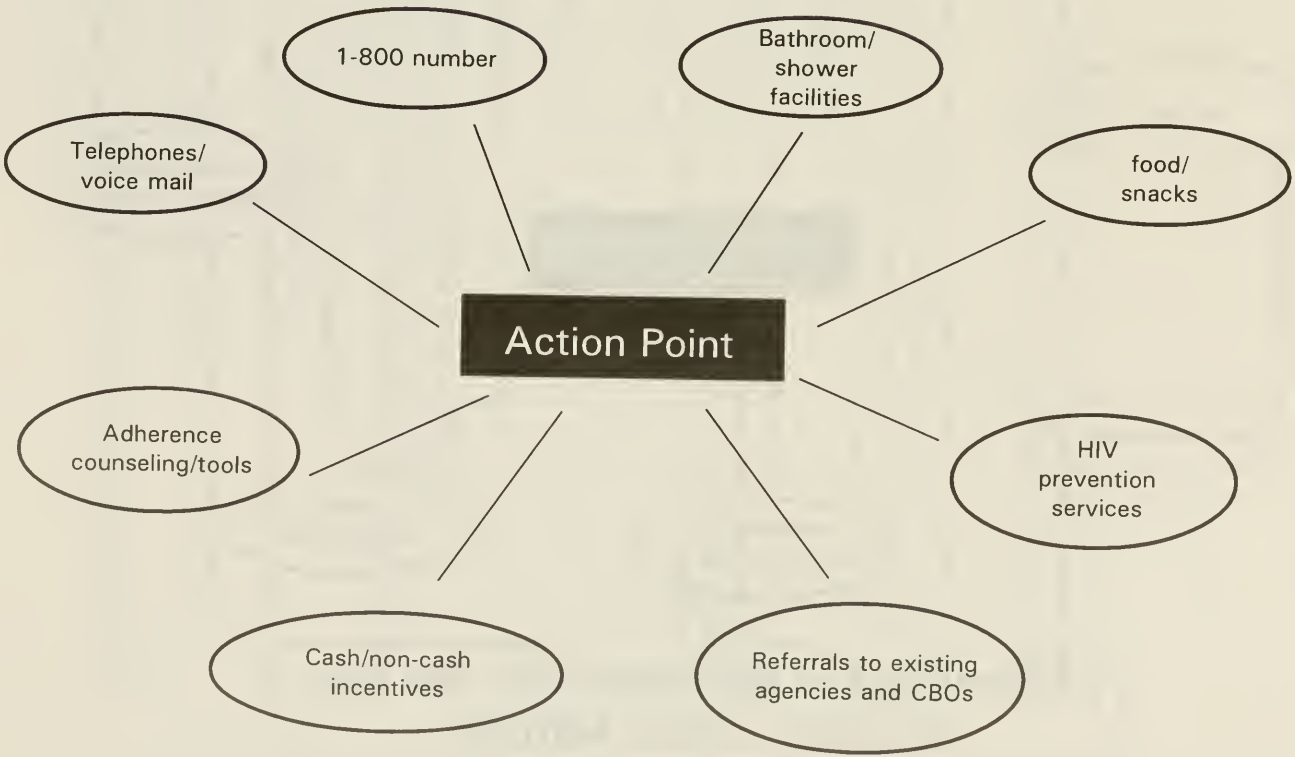
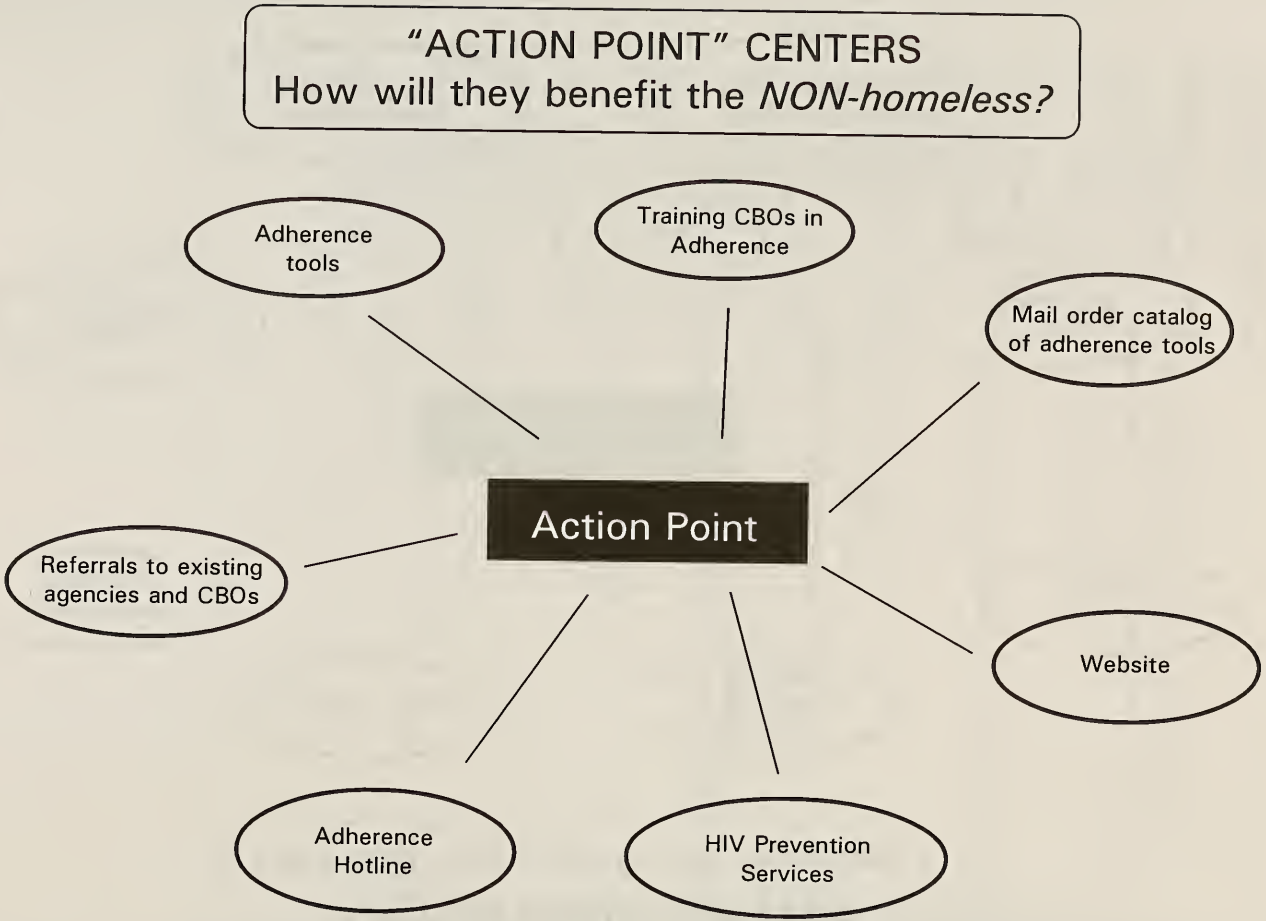
"ACTION POINT" CENTERS
How will they benefit the homeless?




"ACTION POINT" CENTERS
How will they benefit the *NON-homeless?*
Adherence tools
Training CBOs in Adherence
Mail order catalog of adherence tools
Action Point
Referrals to existing agencies and CBOs
Website
Adherence Hotline
HIV Prevention Services

Insurance Issues
Subcommittee Report

Goal

Using its influence as a purchaser and provider of health care, and its relationship with the business community, the City of San Francisco has an opportunity to improve the quality and access to health care for persons with HIV by:

- Assuring that high quality, comprehensive health care services are available, accessible, and affordable
- Protecting its residents from discrimination, fraud and abuse, and
- Advocating for its residents in the public policy and health care benefits purchasing arenas.

San Francisco has the opportunity to lead in the development of quality standards which can be used in the purchase and provision of health care services for its residents and employees. Quality HIV care results in improved prognosis and quality of life for HIV positive individuals and can also reduce HIV care costs.

Background

San Francisco is an HIV/AIDS epicenter:

- 24,962 total cumulative AIDS cases since 1981
- 7,852 living persons with AIDS as of October, 1997
- Over 15,000 persons estimated living with HIV (or 2.1% of the population)
- Leader in progressive public health policy
- Center of gay culture & politics
- Consistently providing leadership and new models in AIDS care.

California and the Bay Area have also had a significant experience in the managed care market.

- Over 50% of the San Francisco metropolitan area's population is enrolled in an HMO. Managed care arrangements are no longer

limited to the private sector and are also moving rapidly into the Medi-Cal market.

- Purchasers of employee benefits (e.g., large employers, PBGH, CalPERS) have successfully bargained for more competitive pricing of health insurance coverage. Market forces, to date, have brought down health benefit costs because buyers have focused on *price*, now they are beginning to focus on *quality*.

- Health plans (HMOs) have shifted financial risk, through capitation, down to provider groups also known as Independent Practice Associations (IPAs). Providers have thus taken on greater fiscal management responsibility, along with the management of more complex and expensive care (in some cases, including home health care and pharmacy management).

- Attempts to monitor the effects of such changes not kept pace with the marketplace, especially as insurers (HMOs) move further away from direct management of medical care, and most of the "action" occurs on the provider group level

Introduction

Assumptions commonly used in managed care markets don't necessarily hold true in San Francisco, where there are numerous obstacles and challenges to ensuring a level playing field for health care providers and consumers.

- Insurance rates are based on the assumption that a population of insured includes many who are "well" and some who are "sick." Because San Francisco is an AIDS epicenter, we have a disproportionate number (an estimated 2.1% of the population) who need care because they have HIV or AIDS. Therefore, rates based on a "regular" population (not as hard hit by the epidemic) result in insufficient reimbursement rates for HIV/AIDS care for SF providers.

- San Francisco providers have generally kept pace with a continually "moving target" of a "community standard" of HIV care. That standard is often well ahead of national standards in the use of new treatments or application of new technologies, which require keeping pace with: experimental therapies, off-label use of medications, and the use of clinical trial data in treatment

decisions. These technologies are similarly not accounted for by rates, which are based on historical service use.

- There are multiple models of managed care – at both clinical and financial levels – making it hard to determine who should be accountable for what. This is reflective of a very competitive environment in San Francisco – where some competitors (this could mean payers, plans, or medical groups) may not want a level playing field.

- There are high levels of consumer confusion due to uneven and imperfect information about options and implications of choices. This is true for individual consumers of health care, as well as for purchasers of health care insurance (employers). In addition, the health care environment is changing rapidly.

San Francisco can play a unique leadership role, as:

- Employer – the City and County of San Francisco purchases health care benefits for over 100,000 of its employees/retirees
- Contractor – using its leverage as a payer to help assure similar quality HIV care to those who receive health care benefits through its contractors/contracting agencies
- Provider of health care to City residents, especially those who are indigent
- Partner with major corporations in the City-many of whom represent large employers in SF and the Bay Area
- Leader, with our Mayor – taking advantage of our influence with other Mayors, the State, and the on the national level in public health policy, and
- Long-term visionary-in its current planning for universal health care its residents. Our recommendations will be shared with the Mayor's Blue Ribbon panel to assure that all providers of health care services must be held to same standards for quality of care and information to consumers.

The recommendations do not single out public sector health care such as Medi-Cal or Medicare. All health care providers should be held to the same high standards regardless of funding source. Because public sector funds are increasingly moving to the use of private sector "managed care" models, the following recommendations focus on the principles of managed care which can be identified and highlighted to assure quality care to persons with HIV.

Recommendations

1. *Health plans and their providers should adopt existing standards as a minimum baseline for HIV care and use those standards to continually assess and improve quality of care.*

These standards must be interpreted as providing helpful guidelines for clinical care, and provide guidance on the **minimum** expectations of care. Especially in light of the rapidly changing "state of the art," guidelines do NOT represent strict algorithms for clinical HIV care. Standards should include the provision of HIV prevention information to all beneficiaries and the promotion of HIV counseling and testing. Similarly, care for the persons with HIV must be individualized, with adequate information provided to help inform treatment decisions, and support to improve adherence to treatment regimens. [See Bibliography for a list of existing standards and their source information.]

Plans must have a system for adopting and updating standards of HIV care in a timely fashion, via an advisory system which should include (at minimum) providers with HIV/AIDS expertise and consumers.

HIV disease should be given the same priority in the development of quality measures, as any other measured disease (e.g., diabetes), which result in quality outcome data. Performance measures based on current clinical standards should be used-measures such as the use of PCP prophylaxis, Pap smear rates, and PPD screening rates.

2. *Health plans doing business in SF should have adequate numbers of providers within their network with HIV expertise.*

Providers with HIV expertise should be identified and allowed to act as primary care providers (PCPS) for patients with HIV. It is understood that providers who choose to act as PCPs must be able to provide the full scope of primary care services. Studies (Kitahata, NEJM 1996) and experience have shown that providers with significant experience in HIV care provide better quality and more cost-effective care.

At present, there is no formal certification for HIV expertise, but various groups (such as the Infectious Disease Society of America) are currently developing such criteria. In the meantime, **Plans and IPAs should encourage and support providers** to **self-identify as having**

HIV **expertise.** This policy would not only improve the quality of HIV care, but also improve consumer satisfaction.

Identification of HIV experts may cause concerns about adversely selecting persons with HIV into specific plans or IPAS. Therefore, to maintain a more level playing field, **purchasers should require ALL participating health plans to include HIV experts in their networks AND make those names available at the time beneficiaries choose their plans and providers.**

3. *Because of the complex medical needs of persons with HIV and AIDS, timely access to specialty/subspecialty services must be assured.*

Within specialty and subspecialty areas, providers with HIV expertise and experience should similarly be included and identified.

When HIV expertise in specific specialty/subspecialty areas is not available within provider networks, then the Plan should provide a clear (and unencumbered) mechanism for patients to go for care either within Plan (e.g., between IPAS) or out-of-plan for their care. It should be noted, however, that mechanisms of access to specialty and subspecialty services are usually determined at the IPA level. Nonetheless, recipients must be given information about how to access specialty care.

4. *Plans providing care in San Francisco must have a mechanism to assure the development and maintenance of appropriate formularies for HIV/AIDS care.*

For persons with HIV, **access to all FDA approved HIV therapies must be assured,** either through inclusion on the formulary, or via an expedited (and uncomplicated) review process. When review is required, that mechanism must be made clear to the providers and beneficiaries. Health plan formularies cannot legally be "closed" in California and must include all medically necessary interventions. This needs to be understood and enforced when physician groups assume pharmacy risk.

Formulary (pharmacy and therapeutics) review committees should either include persons with HIV expertise, or have a mechanism to regularly receive input from HIV experts. Formulary review should occur at least quarterly and a mechanism should be in place to ensure more rapid review and availability when new drugs are approved.

Because San Francisco has a significant population of patients who are antiretroviral treatment "experienced," the review process must take into account their need to access approved drugs for off-label indications, and in some cases, their need for more atypical antiretroviral regimens. Those requests should undergo expedited case-by-case review by HIV experts.

5. *Reimbursement for HIV care must be restructured to account for the prevalence of HIV in San Francisco.*

Financing mechanisms must not serve as a disincentive to provide care to people with HIV/AIDS, nor a disincentive to employers to cover their employees, nor to developing expertise in HIV care.

One of the following financing mechanisms must be developed and adopted:

- Risk (severity) adjusted capitation rate (current capitation is based solely on an age and gender adjusted basis), or
- An HIV/AIDS carve out, where HIV care is paid for on a negotiated fee-for-service basis.

The methodology of estimating costs is now sufficiently advanced to allow either of those mechanisms to be used.

All levels of providers, depending on the level of financial risk assumption, including plans, physician groups, and individual providers must be appropriately reimbursed to provide quality and cost-effective care. Financial incentive changes must reach down to individual providers in order to be effective in addressing the issue of maintaining and encouraging HIV expertise.

In addition, there must be a process for monitoring future changes in costs, and evaluating the effectiveness of the reimbursement mechanisms and incentive structures.

6. *All plans serving San Francisco should, at a minimum, be required to provide vital information in clear written form to any prospective and/or enrolled plan members who request it.*

The City & County of San Francisco, in conjunction with plans and providers, must determine how best to get this information to consumers in a

timely and useable fashion. The information should be available in all languages considered to be "threshold languages" by the California Department of Health Services for the purposes of administering Medi-Cal services. The necessary information includes:

- The names of identified HIV-knowledgeable providers, specialists, and sub-specialists
- The plan's formulary
- The plan's policy regarding off-label and experimental treatments
- The plan's policy regarding participation in clinical trials
- An explanation of any HIV-specific services offered by the plan and provider group.

There is additional information that could help consumers make more educated and informed decisions regarding their health care, but which is more difficult to provide. Some of these are controlled at the plan level, some at the IPA, and some by individual providers. Consumers need to be educated about where this information is available, and where these decisions are made. These are examples of such information:

- The process for approval of non-formulary therapeutics including any appropriate time line or waiting period
- The process for formulary additions and deletions
- The plan's policy regarding referrals to specialty care, including the standard timeline
- A clear explanation of mental health and substance abuse benefits
- Explanation of inpatient benefits including any limitations
- Explanation of home health care and home hospice care benefits including limitations
- An explanation of any limitations on medical devices
- An explanation of the plan grievance and appeals process with standard timelines.

The City & County of San Francisco has the responsibility as an employer to ensure that this information is provided to its employees during open enrollment, and has the opportunity to exert the leadership needed to ensure that this information is made available to all health care consumers.

Next Steps/Action Plan

The Mayor should review these recommendations for adoption as a purchaser of health care benefits and should work actively with other local

purchasers of health care benefits (e.g., the Pacific Business Group on Health) to lead in HIV care standards.

Recommendations can be adopted in the form of an informational checklist, by requiring all participating health plans to report on how they meet the following criteria:

- HIV advisory system (and who they are)
- Use of HIV care standards (what and how)
- Identified providers with HIV expertise
  - HIV experts as primary care providers
  - Specialists/subspecialists with HIV expertise
  - Listing these providers for consumer use
- Assured timely access to HIV drugs
  - Identification of formulary policies/procedures re: HIV drugs
  - Making drug access information available to consumers
  - Use of HIV experts in updating formulary
- How the plan addresses financial disincentives to concentrate HW care and expertise
- Full and clear explanations of benefits, the grievance process, and drug coverage information for consumers.

As a public entity, the City and County should make this information available to its beneficiaries at the time they choose their health plan.

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Long-term Disability Insurance Issues

Goal

Using its influence as a purchaser and provider of employee benefits, and its relationship with the business community, the City of San Francisco has an opportunity to help remove disincentives to returning to work for people who are disabled by HIV and AIDS. The City can foster workplace re-entry by advocating that private and public employers negotiate long-term disability insurance contract provisions which allow the disabled to attempt full-time work reentry while maintaining their ability to continue eligibility for benefits should they need to discontinue work.

Background

Due to improved health status, many people disabled by HIV and AIDS are considering reemployment. We currently do not know if persons returning to work will be able to sustain employment. Many long-term disability policy provisions act as a disincentive for individuals faced with the prospect of losing income benefits if they should return to work for more than six months.

Introduction

Returning to work is a disincentive under current long-term disability insurance industry practices.

If a disabled individual receiving long-term disability income returns to work, they often face loss of coverage if they work full-time more than six months (often called the Recurrent Disability Provision). The individual returning to work may be offered a new group long-term disability plan; however, there will be both a service waiting period for enrollment and a pre-existing condition exclusion which, together, can deny coverage for up to 24 months.

Recommendations

1. *Insurance companies should adopt standard long-term disability provisions to allow disabled persons to attempt employment while maintaining their ability to continue eligibility for benefits should they need to discontinue work.*

Recurrent Disability Provision: Create a minimum standard of continued coverage for 24 months or until the individual is covered under a comparable plan, whichever is sooner. Although there is no premium paid during this period of working, no benefits are paid to the covered individual, thus creating a win-win situation for both the insured and the insurer.

Residual/Partial Disability Provision: Allow part-time work with a reduction in – but not elimination of – long-term disability benefits. Combined wages and the reduced long-term disability benefit should be higher than the long-term disability income benefit alone as an additional work incentive to the disabled individual.

Rehabilitation Provision: Allow continued coverage (we recommend up to 36 months) while the disabled individual is in a rehabilitation program approved by the insurer involving preparation for return to work.

2. *Long-term disability insurance group coverage should be a benefit that is available to all employees of organizations with more than 10 employees.*

The City of San Francisco currently offers private long term disability insurance benefits through a single private plan that is paid entirely by the employee; however, this plan is not available to individuals with a pre-existing condition such as HIV/AIDS. *NOTE*: Some City employees are covered by union long-term disability plans and/or some are eligible for disability retirement benefits but only after 10 years of employment. The City, and all employers with large numbers of employees, should offer one or more group long-term disability policies to all employees that incorporates the above recommendations.

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Testing, Surveillance and Reporting Subcommittee Report

Introduction

The first test for the presence of HIV infection was developed in 1985. This test – actually an antibody detection test – was immediately put to use in the screening of blood and tissue donors and donations, with considerable success in reducing risk of transfusion and transplantation-associated AIDS. Beyond this application, however, HIV testing – and its uses – have long been controversial.

The debates have included many questions: How accurate are HIV tests? What are the psychological and behavioral impacts of taking the tests? What kind of confidentiality, consent and counseling policies should apply to testing? Are there ever justifications for requiring HIV testing? When, if ever, should test results be disclosed to third parties such as health officials, medical providers or others potentially "needing to know?" What are the best ways to utilize and target testing efforts? What is the most ethical and most sound public health strategy regarding HIV testing, reporting and notification that respects both individual rights and societal needs? Will the desire for more accurate HIV surveillance data lead to the development of testing schemes that drive many at risk away from testing?

The answers to some of these questions have remained consistent over time, while others have evolved with the epidemic itself. Some populations at risk for HIV infection have been under-served by HIV testing and counseling services; new treatments for HIV infection have altered the framework surrounding HIV testing and reporting; new HIV testing technologies have been developed; and legal and fiscal requirements related to HIV testing and reporting continue to evolve. Some of these developments entail primarily technical responses, while others – such as the reporting of HIV test results to public health officials – bring strong emotional, ethical and political forces into play.

In the year preceding the San Francisco Mayor's HIV Summit, a growing national debate regarding the collection of HIV surveillance information and the reporting of the names of those testing positive has again awakened long-past arguments and divided long-time allies. In California, community forums have been held in San Francisco and Oakland, with a statewide discussion also occurring. San Francisco, which as served as a model for so many other approaches in the response to the HIV

epidemic, is now presented with an opportunity to provide new leadership on the complex and contentious issues related to HIV testing, surveillance and reporting. Our recommendations reflect in-depth discussion among a diverse group of people with long experience confronting these issues in San Francisco and elsewhere, as well as the opinions presented during the community and statewide forums noted above. We offer these proposals with the hope that our City will continue to lead the way in providing sound policies for both preventing new cases of HIV infection and assisting those affected or infected with HIV as we move into the third decade of this epidemic.

The Testing, Surveillance and Reporting Subcommittee of the Mayor's Summit had as its mission:

> *To provide the Mayor of the City of San Francisco with recommendations on the appropriate and optimal role of such tools as HIV surveillance, testing, counseling and linkage to services, reporting and partner notification, given 'the new era of HIV' – as defined by new treatments and new testing technologies. These recommendations will be provided in order that the City of San Francisco may take a leading role with regard to public policy decisions at the City, State and Federal levels on the development of productive models for confronting these complex and contentious issues. Public health, legal, civil liberties and HIV-specific perspectives – along with an understanding of the implications of these issues for diverse HIV-infected and HIV-affected populations and communities – will be taken into account in developing the recommendations.*

HIV Antibody Testing

Many people report that HIV testing was their first encounter with substantive HIV education and prevention information. Many people find access to care for HIV (as well as for substance abuse, mental health concerns and sexually transmitted diseases) through their HIV counseling and testing encounter. In fact, for many at-risk individuals, including adolescents, commercial sex workers and the working (uninsured) poor, their HIV counseling and testing experience represents a first encounter with the health care delivery system and their first opportunity to gain access to health care and meaningful social services for themselves and their families.

Testing *must* be available at both confidential and anonymous testing sites, to ensure that the greatest numbers of individuals are offered the

opportunity to obtain testing and counseling in a safe environment of their choosing. *(Anonymous* testing means that no medical record is kept of an individual's HIV test or the result and no names are given. A code is used for reserving appointments and for obtaining test results. *Confidential* testing means that a confidential medical record is kept of an individual's HIV antibody test and the result. Confidential test results may not be released without the patient's consent or a court order.) Many studies have shown, and many people have stated, that anonymous testing sites are critically important due to the fact that AIDS-based discrimination continues to exist. People testing positive have concerns regarding their privacy within their communities. They have concerns regarding how best to deal with a positive test result with their family, their employment, the legal system, the insurance industry, the educational system, the Immigration and Naturalization Service (INS) and other governmental bodies, and others. Both confidential and anonymous testing sites can enable people who test positive to obtain access to care.

Anonymous test sites *must* be available throughout the country. Particularly if a national HIV surveillance system is implemented state-by-state, wide availability of anonymous test sites (as distinct from the mere availability of home testing options) must be mandated as a condition of all Centers for Disease Control (CDC) HIV Prevention Cooperative Agreements. All anonymous test sites must be funded to include appropriate counseling by individuals trained in voluntary, client-centered, nonjudgmental, non-coercive approaches that include behavioral change, harm reduction, culturally competent and gender and age appropriate strategies. Individuals must be equipped with the skills to identify and assess risk and make appropriate referrals and transfers to care and services, whether they test positive or negative.

The inclination to seek testing depends in large part upon one's experience with societal discrimination and one's beliefs about the epidemic. The perception of risk (both social and medical) and the belief that finding out one is HIV-positive are significant determinants in seeking testing. One must believe that testing is important and that a positive difference can be made in one's life with that knowledge (e.g., that effective treatments exist and will be available) – such that the fear of potential AIDS-based discrimination is offset by these beliefs. Denial and other psychological mechanisms to avoid thinking about the terrifying topic of HIV also seem to undermine willingness to be tested.

One way to overcome some of these psychological barriers and encourage more widespread voluntary testing is to get the word out about the tremendous potential benefit of finding out about HIV early in the course of

infection. Although long-term information on the new combination therapies is not yet available, although a "cure" may be a long way off and "eradication" of the virus may be an elusive goal, and although certain populations appear to be accessing therapies less readily or potentially with less success, the new therapies offer tremendous opportunities and hope. Everyone who is HIV-positive or who may have been exposed to HIV deserves the opportunity to find out her or his HIV serostatus and begin an immediate examination of treatment and monitoring options. Given the extent to which poor people, people of color and those already disenfranchised from society are over-represented in the HIV epidemic, it is essential that prevention, testing and treatment messages address specific concerns and confront the mistrust felt by marginalized and stigmatized individuals.

Recommendation:

1. *The City and County of San Francisco, together with public health leaders and local church and civic leaders who have "bully pulpits" of their own, should offer leadership to other city and state leaders, as well as to federal policy makers, in encouraging more widespread voluntary HIV testing within a counseling context as an important element in fighting this epidemic, particularly among those at highest risk for HIV infection. The maintenance and expansion of funded anonymous test sites must be a part of this effort.*

Mandatory HIV Testing

HIV antibody testing must be *voluntary.* The decision to be tested is, and must remain, a personal and individual one that should be made after a personal risk assessment. An individual should be properly informed about the benefits and risks of taking the antibody test and weigh these issues before making a decision.

Mandatory testing of any segment of the population is an ineffective means of stopping the spread of HIV, a basic violation of individual rights to privacy, and is a wasteful use of scarce resources. Such testing policies are not cost effective and have the potential to discourage and distract individuals from seeking necessary services and/or adopting behavioral changes that offer effective protection from infection. In addition, testing should never be undertaken without the knowledge of the test subject or proxy, nor should it be done without HIV-specific informed consent, preferably in writing. (The one exception to this requirement is blinded seroprevalence studies which form the backbone of the sentinel surveillance system for HIV infection and where no linkage exists between test subject

and test result.) Mandatory testing should be limited to blood, blood product, organ, tissue and sperm donors. For the protection of donated blood, blood products, organs, tissue and sperm, donors of such products should be informed that they will be tested for HIV, with HIV-infected donors excluded from further donations.

In recent years, there has been particularly heated debate regarding mandatory HIV testing of pregnant women and/or newborns. Such policies would risk accomplishing little more than driving some women and children away from the health care setting, while violating their civil rights and civil liberties in the process. A number of recent studies and/or surveys have shown that if pregnant women are counseled in a non-coercive manner about HIV testing, the vast majority will choose to be tested voluntarily. Recognizing the benefits of counseling and voluntary testing, the CDC published sound guidelines in 1995 on this issue, which recommended counseling pregnant women regarding HIV testing. The California Legislature later passed a bill in 1995 that required all prenatal care providers to counsel pregnant women regarding HIV and to offer an HIV test. Additional HIV testing policies related to these populations should continue to encourage non-coercive counseling and access to voluntary HIV testing.

Recommendations:

1. *The City and County of San Francisco should advocate for policies that promote voluntary HIV testing at all levels of government.*

2. *The City and County of San Francisco should vigorously oppose any policies that mandate HIV testing of any population group or in any particular setting, except in the case of blood, blood product, organ, tissue or sperm donation. The City should also oppose and disallow any efforts to test individuals without their knowledge or informed consent.*

3. *The City and County of San Francisco should support policies that promote non-coercive HIV counseling and access to voluntary testing, particularly in the case of pregnant women and/or newborns.*

Expanding Testing Options

Some of the factors deterring individuals from seeking testing may be addressed by making tests available in varied settings. Where there is a concern about anonymity, home test collection kits may assuage this, but

they also may be prohibitively expensive (at $30-50) for those most in need and may not provide adequate counseling services and information to those at greatest risk of contracting HIV. Thus, it is essential to continue to make free HIV testing available at anonymous test sites. Private clinicians and care providers should also be encouraged to offer voluntary HIV testing more routinely (although never, obviously, without discussing risks and benefits and obtaining informed consent). It also makes sense to encourage greater HIV testing efforts as part of family planning, drug and alcohol abuse treatment, and tuberculosis treatment.

The decision to get tested is not always a steadfast one. It may be fleeting, relating to the moment and the circumstances. Many people seek out testing when embarking on a new relationship, when seeking out medical treatment or because they find out a partner may have put them at risk. Whatever the reason, it is important that testing programs be immediately available for those willing to undergo HIV testing voluntarily.

Public officials and health care providers have a responsibility to topple as many barriers to HIV testing as possible. This means making tests available at no cost or low cost; reducing waiting times for test appointments; reducing waiting times for returning for results or collapsing the process into a single visit; making various testing technologies available; and providing community testing and other outreach services and referrals for those who might be at high risk and willing to be tested. The use of mobile vans and incentives to encourage individuals to be tested should be utilized.

Recent years have seen advances in testing technologies. Home test collection kits were approved in 1995 by the FDA for individual use, with one brand currently available in most local drug stores and through the mail. Home test collection is perhaps the most anonymous option available, involving sending a blood sample to a lab and receiving results and phone counseling based on an anonymous bar code number. Although the retail cost of these tests remains quite high, there are opportunities for savings through bulk purchases by public health agencies or community groups. However, there appears to be uneven counseling provided; more usage of these tests by those who are white; more access by those with the education and language skills to understand the test instructions; and overall, little interest in this method of testing. Additionally, a small number of those utilizing the test kits appear to test positive: in a three-month period in California, four people tested positive (for a rate of 0.8%, with the statewide average in public funded test sites approximately 1.4%). Anonymous testing must continue to be made available through other means.

Also relatively recent are oral fluid tests. These tests are as accurate as conventional HIV antibody blood tests. They obviate the need for a blood

draw, although still requiring the involvement of a health care professional and the sending of results to a laboratory. Bypassing a needle stick is a welcome option for many clients, particularly injection drug users. Oral fluid tests also reduce the biohazard of needlesticks to health care workers and may eventually be more readily used in a variety of street, community and outreach settings. Oral fluid *home testing* may also be available in the future.

In some local settings, health care workers offer other rapid tests which yield results within hours, rather than days. These tests can rule out HIV-negative individuals, although they would require a confirmatory test for those whose results are initially positive. More clinics and care providers may wish to investigate adopting testing technologies and procedures that produce accurate and reliable results more quickly. Rapid tests help deal with those who don't return after the initial test and thus miss the opportunity to receive their test results and have post-test counseling. (One study showed that in *confidential* test sites – primarily STD clinics – the rate of those who did not return for their test results was 30.4%.) However, with rapid tests, while individuals are able to receive their test results without a return visit, there is still no second chance to do counseling. That is a particular cause for concern with those who are at "high risk" although testing negative. This raises the question as to how we might need to reengineer counseling with the emergence of the rapid test. There is also a high number of false positives with rapid tests. Currently, the wait for receiving "rapid" test results is about two hours (instead of ten minutes, as is commonly thought), with confirmatory test results back in one week. The possibility of rapid *oral* tests is also currently being investigated.

Other new testing technologies include urine-based tests and the HIV Shiloov Tube. The specificity and sensitivity of urine-based tests is not as good as serum-based tests and no confirmatory test is yet available. This testing technology is thought to be particularly useful for health care workers (again, due to reduction of the biohazard of needlesticks) and their clients, especially injection drug users. These tests are currently mostly being used by insurance companies for screening purposes. The waiting period for identifying HIV antibodies is reduced to 1-2 weeks (as opposed to up to 6 months) with the HIV Shiloov Tube. This would be used particularly for blood donations and public health purposes. Developed in Israel, the U.S. will be investigating this new technology during 1998.

The "detuned" ELISA is not yet FDA-approved. It is a less sensitive ELISA used only for confirming those who are positive. This testing technology can indicate earlier infections (within 120 days), and thus has implications for partner notification.

This is a dynamic time in the course of the epidemic. San Francisco is leading the nation in making testing and treatment options available at the earliest stage of infection and throughout the course of HIV disease. Individuals who believe they may have been exposed to HIV as a result of unsafe sex or needle sharing can now avail themselves of free, "post-exposure prevention" counseling and treatment. Other programs seek out individuals for follow-up care who experience the flu-like symptoms associated with seroconversion following an exposure in recent weeks or months. For those who find out they are HIV-positive, there are a growing range of options for monitoring the level of the virus in the blood and other tissues, as well as for measuring the resistance to various AIDS drug combinations. The testing environment thus must be utilized not only to provide appropriate counseling, but also to offer a point of access to care and services. In order to fully meet the needs of people who are tested, services must be available to those who need and want them.

Thus, services should be expanded to include mental health, substance abuse and medical care on demand.

Recommendations:

1. *The City and County of San Francisco should explore the possible usage and various implications of new testing technologies as they become available.*

2. *The City and County of San Francisco should gauge the accessibility of HIV testing to those in need. This will entail a close look at the local landscape of HIV infection, down to the neighborhood level. It will also involve assessing any barriers to voluntary testing that may remain in terms of cost, travel time, waiting time, availability of culturally competent counselors and materials in languages other than English. The drive for earlier intervention and the melding of prevention and care concerns underscores the importance of providing ready access to the health care system for those who find out they are HIV-positive. Ongoing assessment of access to testing and the nature of associated counseling should include much greater attention to the ability of prevention programs and agencies to relate to providers of clinical care. A six-month study undertaken by San Francisco should critically assess the role of various public and private sector agencies in making no cost or low cost testing available to those at risk in a fashion that will encourage widespread, voluntary testing. It is worth undertaking this effort in conjunction with San Francisco's participation in the National Day of Testing, an occasion that*

needs more focused attention and that can be used both to push for more widespread - yet voluntary - testing and to confront gaps in ongoing service programs.

HIV Counseling and Referral Services

HIV counseling services offer a unique opportunity for an individual to learn about HIV testing, assess their risk, develop a behavioral change plan and address their fears and concerns about HIV. Whether in the public or private sector, HIV counseling should be offered widely at a variety of accessible times and places at both anonymous and confidential testing sites. HIV counseling must be voluntary, client-centered, non-judgmental and non-coercive. The national standard for appropriate counseling messages must be updated in cooperation with statewide community planning groups and issued in the form of CDC guidance. It should utilize behavioral change approaches and harm reduction strategies and be culturally competent and gender and age appropriate. Counseling services must be a part of the standard of care for all those who test for HIV, and HIV test results should always be disclosed in the context of a counseling session. Adequate funding for counseling and testing and prevention services must continue to be provided and advocated for as categorical funding distinct from treatment (i.e. ADAP, or AIDS Drug Assistance Program) funding. Referrals and linkages to services are an essential step in ensuring the continuum of a client-centered care system, the appropriate use of public and private programs and resources, and the avoidance of duplication of services.

Recommendations:

1. *Pre-test counseling in both the public and private sector should include a risk assessment and the development of a behavioral change plan by the client.*

2. *Post-test counseling in both the private and public sectors should include disclosure of HIV test results, review of the behavioral change plan and appropriate referrals to other services.*

3. *For those who test HIV-positive, counseling should include the provision of emotional support and information on safer sex practices, partner notification services and information, and referral and linkage to an HIV (early) care program, or other HIV-related services, as appropriate (see #13, below).*

4. *For those who test HIV-negative and are at "high risk" of HIV infection or reinfection, other forms of "enhanced" counseling and prevention case management, including review of the client's behavioral change plan and safer sex practices, should be offered, as should referrals and linkages to prevention services for HIV-negative clients.*

5. *Follow-up counseling sessions should be available and offered, if needed, for those testing HIV-negative or HIV-positive.*

6. *All providers in the public and private sectors who conduct HIV testing should be required to provide HIV counseling and should be certified in pre-test and post-test counseling at the County and State levels and trained in voluntary, client-centered, non-judgmental, non-coercive approaches and behavioral change, harm reduction, culturally competent, and gender and age appropriate strategies. Documentation that counseling services were offered and/or provided (as distinct from HIV testing services) should be maintained.*

7. *A state-of-the-art knowledge base of HIV counseling services for various populations must be maintained and updated for all counseling service providers in both the public and private sectors.*

8. *A program offering courses in pre- and post-test counseling, and voluntary, client-centered, nonjudgmental and non-coercive approaches, along with behavioral change, harm reduction, culturally competent, and gender and age appropriate strategies, must be required for all HIV counseling providers in both the public and private sectors. This program must include ongoing training and proficiency standards in any current changes in the epidemic (such as increased availability of combination therapies or post-exposure prevention therapy).*

9. *Referrals must be part of the standard of care for all clients who test for HIV, whether testing positive or negative. Referrals should be provided at all points within the testing and counseling system, as well as when an individual is receiving prevention, care and treatment services (i.e. at pretest and post-test counseling sites, early intervention centers, etc.).*

10. *Mechanisms such as linkage agreements and memoranda of understanding to facilitate the linking of clients to appropriate care and prevention service providers should be developed and maintained. Documentation should be kept that referrals were made.*

11. *All testing counselors and direct service providers, including those in the private sector, should be trained to give appropriate, up-to-date referrals and should utilize a state-of-the-art knowledge base of referrals and resources for people who are HIV-positive or HIV-negative.*

12. *Resource lists and referral manuals should be compiled and maintained in various languages. Resources and referrals must also be geographically, culturally, gender and age-appropriate.*

13. *A select list of critically-needed, current referrals must be developed with the expertise of community planning groups and provided to all at-risk clients who test for HIV, including those who test positive or negative. This list must include prevention referrals and referrals for HIV (early) care and other medical services, psycho-social (including mental health and substance abuse) support, and additional health and social services, as appropriate to HIV-positive or HIV-negative clients.*

Partner Notification

Voluntary partner notification services should be offered to all persons testing positive for HIV, whether in the public or private health sector. These services should consist of counseling the person who tests positive and assisting them in the notification of any potentially exposed sexual and/or needle sharing partners. These services should be offered in order to give persons who may have been exposed to the virus an opportunity to receive HIV counseling, get tested for HIV, change behaviors that may have put them and others at risk, and receive information to prevent the further spread of the virus. We do *not* support the creation of a federally-based partner notification system.

Recommendations:

1. *All providers in the public and private sector who are responsible for disclosing HIV-positive results to clients should be educated regarding the availability of public partner notification services and encouraged to use those services. Providers should be trained in the various methods for partner notification, including client self-referral, provider referral, counselor-facilitated notification and combinations of these approaches. All providers, private and public, who are responsible for partner notification should be certified. To this end, courses need to be offered in partner notification for private providers and public programs.*

2. *Partner notification services should always be voluntary, index/original client-centered, non-coercive and confidential, without disclosing any identifying information about the original client or specific time of possible infection. (The potential application of the detuned ELISA for identification of recent infections raises new issues regarding how specific providers should be about the time duration of the possible exposure; however, no information should ever be provided that would enable the partner to identify the index client.) The index/original client should be offered extensive information as to the range of issues contained in partner notification, including the possible responses they may expect from partners whom they choose to notify. Assistance should be offered in order to help the client better understand both how to carry out partner notification, as well as the ramifications (pro and con) of partner notification. An offer on the part of the partner notification program to do partner notification for the client should only be made in consultation with the client, sensitively and non-coercively, and in cases where the client is unable or unwilling to do partner notification herself/himself and wishes assistance from the program. Partner notification services should not be linked in any way to surveillance systems.*

3. *Partner notification services should be offered in the context of post-test/disclosure counseling, follow-up counseling, during medical appointments and intake to HIV care programs and as part of case management for all those who test HIV-positive in both the public and private sectors. Documentation that these services were offered should be maintained.*

4. *Partner notification services should become part of the standard of care for those who test HIV-positive and viewed as the fourth step to take in the process (after receiving emotional support, obtaining referrals and linkages to appropriate medical care and other social services, and developing a behavioral change plan). Voluntary, non-coercive partner notification services should be better promoted and evaluated according to the standards noted herein. Any increased costs for such services should not be allocated from other HIV prevention or care services.*

5. *A state-of-the-art knowledge base of HIV testing services (both anonymous and confidential), HIV prevention counseling services (both public and private), and HIV (early) care programs (both public and private) should be maintained and updated for all partner notification providers in the public and private sectors so that they will have the capacity to make appropriate referrals.*

6. *A partner notification program should be maintained which provides consultation, technical assistance and training to HIV counseling and testing service providers in both the public and private sectors. Private providers should be actively educated as to the availability of this program.*

HIV Surveillance and Reporting

Reporting HIV test results to public health officials and to agencies in either the public or private sectors has long been of concern. Fears of various forms of discrimination if test results were to be known by "third parties" of any type resulted in a consensus that such testing would be voluntary, confidential, and often anonymous, with no reporting to public health or other public or private parties without the explicit consent of the patient. With few modifications over the years, this has been the policy in San Francisco and, in fact in much of the rest of the state and nation. The San Francisco Health Commission's current policy on this issue states San Francisco "is strongly opposed to State legislation which would require the reporting of names of HIV-infected persons in San Francisco to County health authorities."

In California as a whole, an AIDS diagnosis is a reportable condition, but HIV infection is not. HIV is currently reportable by name in adults/ adolescents in 27 states. (As mainly low incidence states, these states account for just 24% of reported AIDS cases.) Two other states report HIV through unique identifier systems, rather than names. (Unique identifiers are number or letter-number codes that correspond to an individual person, location, etc.) In a move highly objectionable to AIDS communities around the country, ten states abandoned their anonymous testing options as they implemented HIV names reporting surveillance systems.

Changes in the epidemic have led many people to express increasing concern that existing AIDS surveillance efforts are becoming outdated. Because new treatment options are thankfully slowing or stopping disease progression in many individuals living with HIV, greater numbers of HIV-infected people are not progressing to AIDS. These people are therefore not being reported systematically to public health entities. As a result, some public health authorities have argued that AIDS case data are becoming less indicative of both the number and the demographics of the HIV-infected populations.

Given these changes, it is not surprising that an increasing number of medical, public health, AIDS organizations and leaders who have historically opposed making HIV a reportable condition are reassessing their position and considering support for some kind of HIV reporting system. A growing movement toward making HIV reportable is underway. While most agree that there is reason for state-by-state HIV surveillance or case reporting systems to be implemented, there is strong disagreement regarding the form that reporting would take, especially given the possibility of deterrence to testing based on the fear of discrimination.

AIDS-based discrimination is still occurring and consequently, continues to be a real concern for many. For example, just recently, the San Francisco AIDS Foundation began asking clients in their 1997/1998 client survey the following question: "If the names of people who tested HIV-positive were reported in a confidential way to a government health agency, how would this have affected your decision to get tested? Forty-two percent responded that they "would not have been tested. " Another question followed: "If you still had the opportunity to be tested at an anonymous test site where no names were reported to a government health agency, but you knew that your name would have been reported to health officials when you sought medical care, how would this have affected your decision to seek medical care?" Thirty-five percent responded that they "would not have sought treatment unless I was very sick." (This data is preliminary and limited; more information is forthcoming in the months ahead.)

Thus, the major point of discussion nationally is whether a names-based reporting system would be utilized, with many advocating a reporting system that is *not* names-based and instead utilizes another form of recording information such as a unique identifier or coded system that would minimize the fear of AIDS-based discrimination.

Benefits and Risks

The goals and benefits of an HIV surveillance system should be:

- Assessment of the demographics and risk profiles affected by the epidemic;
- Planning for future health care and social service needs related to the epidemic;
- Tracking incidence of HIV disease in order to target prevention efforts;
- Evaluation of the impact of prevention efforts; and
- Providing information for rational resource allocation.

With respect to HIV, those benefits apply to varying degrees, but there are risks as well, including:

- Inadvertent or malicious disclosure of names of those infected, including that occurring as a result of legislative or legal mandate;
- Resulting discrimination in employment, housing, insurance, education, etc.;
- Increased disincentives for testing and/or treatment by those fearful of the above; and
- Increased distrust of public health and medical personnel by those most at risk.

As this debate unfolds, it is important to keep in mind the axiom that the trust of the population at risk is a crucial factor in the success of any public health effort. Thus, while the risk/benefit calculation is being re-evaluated and some professional and public opinion may be moving toward some form of HIV reporting, any proposed system *must* balance the proposed benefits versus the risks, real or perceived, and not damage the hard-won trust garnered in this City and in others.

We therefore reaffirm existing City policy opposing name-based reporting. This position is also supported by the prevailing opinion expressed at two San Francisco and Oakland community forums, and a statewide forum that included representatives of approximately 65 community-based organizations from throughout California, all held shortly before the Mayor's HIV Summit. We do *not* support a federal name-based registry of people with HIV and we do *not* support the development of a national standard of state or locally based HIV reporting of names. Further, we encourage the City to endorse and advocate for the following set of essential principles for *any* new HIV reporting system to be developed at the local, state, or national levels:

Principles for any New HIV Monitoring System

- The primary goal of any HIV surveillance system should be to better plan for future service needs, target and evaluate HIV prevention efforts and inform rational resource allocation decisions. *The reporting of names is not necessary in order to effectively monitor the epidemic or provide access to early treatment.*

- A fundamental consideration regarding any HIV surveillance system is that it should not create any disincentive to HIV testing and/or treatment.

- Anonymous test options *must* be maintained and expanded throughout the country, and continue to be promoted and funded as an appropriate means of undergoing HIV counseling and testing. If states are *in any way* required to implement names-based HIV surveillance, including via Federal funding requirements, a similar requirement must apply regarding the availability of anonymous HIV testing in states.

- Existing laws and regulations regarding confidentiality and nondiscrimination protections applying to HIV status and record-keeping, insurance, employment, housing, education and other concerns must be maintained and strengthened where necessary, with heightened civil and criminal penalties for breaches of confidentiality or privacy or for violation of nondiscrimination protections, *before any new HIV surveillance system is implemented.* Federal privacy and anti-discrimination protections are also necessary.

- Any new HIV surveillance system must be adequately funded with *new resources,* and can not be implemented via diversion of funds from existing HIV or other public health programs.

- Partner notification services must continue to operate independently of any new HIV reporting system and shall remain a voluntary service offered to appropriate patients. HIV reporting is not, *in any way,* necessary to improve partner notification efforts.

- An educational outreach program regarding the rationale, procedures, and potential risks of any new HIV reporting system needs to be conducted for both health care providers and the general community.

Given acceptance of the preceding principles, we offer a proposal for implementation specifically in San Francisco.

San Francisco should reaffirm existing Health Commission policy in opposition to name-based reporting of HIV-infected individuals, as there has not been a clear and compelling need demonstrated to change this policy. However, we also affirm the need to carefully and cautiously explore potential improvements in existing AIDS/HIV surveillance efforts. We recommend the following process for development of such improvements:

Recommendations:

1. *San Francisco should convene a task force of appropriate and fully representative community expertise, including people infected and affected by HIV, to develop improvements to our HIV monitoring efforts. The goal should be to develop a model system which is not names-based and maximizes appropriate testing, early detection of HIV infection, evaluation of preventive impact, and tracking and forecasting of HIV infection, but which does not increase disincentives to anyone seeking HIV testing and treatment.*

2. *As one component of this effort, San Francisco should consider the development and evaluation of a new model HIV monitoring system using a unique code/identifier/or computerized encryption option, as a compromise between the existing system of AIDS-only reporting and full mandatory name-linked HIV reporting. The task force should address, at a minimum a) the technical components of such a system; b) the costs of the system and the potential for funding the initial development of such a model system that is outside the current surveillance funding (e.g. private funding); c) the level at which such a system will be created; d) the potential acceptability of the proposed system by both health care providers and patients; and e) the need for specific privacy and confidentiality protections in implementing such a system.*

3. *Both public and private health care providers, and the general public, should be informed and educated about these new efforts and the procedures of any new monitoring system, including confidentiality and nondiscrimination considerations and requirements. The assumption that surveillance systems have the capacity to link individuals being reported to treatment or prevention services must be challenged as part of this outreach process. Instead, education about anonymous and confidential counseling and testing services through which individuals may be provided with appropriate treatment or prevention services, as desired or needed, will be offered.*

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Subcommittee members represent themselves and not necessarily their organizations or departments. While the Subcommittee reached a consensus of opinion on the vast majority of our recommendations, we were not able to on all points. Thus, the totality of our report reflects majority opinion of the Subcommittee.

We acknowledge the work of many people with HIV, activists, policy advocates and researchers whose work and written papers were utilized in our work. In particular, the *San Francisco HIV Prevention Plan,* HIV Prevention Planning Council, December 1996, the *HIV Health Services Comprehensive Five Year Plan: A Client-Centered System of Care,* HIV Health Services Planning Council, February 1995, the *Second Decade Response for HIV/AIDS in San Francisco,* Mayor's and Board of Supervisors Joint Task Force on the HIV Epidemic, December 1994, and the *California HIV Prevention Plan,* California Community Planning Working Group, October 1994, continue to be important guides.

Workplace Entry and Re-Entry Subcommittee Report

1. Introduction: Challenges of System Development

This report summarizes findings and recommendations developed by the Subcommittee on Workplace Entry and Re-Entry of Mayor Brown's AIDS Steering Committee, pursuant to the Mayor's charge to assess the employment service needs of the HIV-positive population of San Francisco and to develop recommendations to establish a programmatically and fiscally effective service delivery system responsive to these needs. These recommendations are intended to assist the City in capitalizing on the opportunities created by the successes of antiretroviral combination therapy to promote the independence and productive employment of San Franciscans living with HIV disease ("consumers"), whose wealth of talent and skills -- if properly supported through the establishment of appropriate services -- could contribute significantly to the success of the local economy, whose growth is beginning to create shortages of labor.

In the remarkably short period of time since their widespread introduction in clinical practice during 1996, the new therapies have significantly changed consumer treatment and social service needs, creating new opportunities and challenges that require, in their turn, reassessment of the City's current approach to AIDS service delivery, funding and policy. The dramatic increase in consumer need for employment services over the past eighteen months strikingly illustrates the impact of the new treatments. The most recent system-wide survey, the San Francisco AIDS Office's 1996 evaluation of consumer needs and satisfaction with Ryan White CARE-funded services, indicates an employment rate of 17% among people with AIDS (9% full-time, 8% part-time), which would translate into employment of some 1,353 out of the 7,963 people living with AIDS in San Francisco as of 31 December 1997. As explained in **section 3** below, the Subcommittee estimates that at least 60% of this population may now be able to enter or re-enter the workforce, provided that the City makes appropriate services available and that current efforts to ameliorate systemic disincentives to employment arising from federal, state and private disability insurance policies meet with at least some success.

The difference between the two rates of employment amounts to more than 3,425 jobs (nearly half the target of 7,500 that motivated San Francisco's enormous effort to respond to welfare reform), and has the potential for significant savings to the City's public health and welfare

systems. As Rick Kemp and James G. Kahn demonstrate in their cost/benefit analysis detailing the distribution of savings attributable to the establishment of HIV/AIDS employment services by payor status, the City and County of San Francisco benefits not only from reductions in County General Assistance, MediCal, and Medically Indigent Program costs, but also from freeing up state and federal resources that can then be redirected to other consumers. Accordingly, implementation of the Subcommittee's recommendations will not only reduce stress upon the City's public health and welfare systems, increasingly burdened due to changes in Federal welfare law, but also facilitate the redirection of the City's public health funding to those most severely disabled. At the same time, an increasing body of research demonstrates that "employment is a treatment that works" (quoting the apt motto of MTS, an employment agency for people with HIV/AIDS in New York) and that people with HIV/AIDS who continue to work enjoy significantly better mental health, fewer opportunistic infections and even longer lifespans than those who cease working.[1]

To capitalize on these opportunities, the City will need to establish a new continuum of HIV/AIDS employment services that assist consumers in surmounting the unique barriers and disincentives to employment specifically arising from their HIV status (see further **section 3** below). Although some HIV/AIDS employment services have been available in San Francisco through two nonprofit agencies, both the range of services and overall system placement capacity need to be considerably expanded in order to take advantage of the opportunities created by the new treatments. Moreover, the limited services that have been available have operated without formal linkage to the CARE-funded system (and therefore without oversight from the Mayor's HIV Health Services Planning Council or the San Francisco AIDS Office) or to the network of employment development resources now organized into the Workforce Development System. As changes in the epidemic have significantly altered consumer needs, it is critical that the City's institutional structures for AIDS planning, evaluation, policy and service oversight be modified to ensure that consumers of care continue to receive services responsive to their needs. In creating an HIV/AIDS employment service delivery system, the City will need to develop new service models, access new funding streams and promote strategic

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[1] Apolonia 1995 reports that full-time employment is a statistically significant indicator of a "31% lower risk rate for death" in the Multicenter AIDS Cohort Study; see the Bibliography printed at the end of this article for full references. See *Vachon 1993, pp. 205-06* for "employment assistance as both a disability prevention strategy and an actual treatment". Studies in progress by *Hooton 1996*, funded by the National Institute on Disability and Rehabilitation Research, further document the impact of vocational rehabilitation services in stabilizing or reversing the decline in functional capacity usually associated with the progression of HIV disease.

alliances with the disability community to enrich AIDS service and policy deliberations.[2]

The network of AIDS social services that has developed in San Francisco over the course of the epidemic is a comprehensive, stand-alone system, relying upon few if any links to other social service delivery systems. This model was created in part in response to the widespread discrimination experienced by gay men and other people with HIV/AIDS in attempting to access mainstream social services in the early years of the epidemic, and since passage of the Ryan White CARE Act it has been considerably expanded and sustained by the City's relatively generous allocation of federal AIDS funding. As changes in the epidemic have altered consumer social service needs, while the very success of the new therapies as well as perceived inequities in the allocation of resources to those affected by other diseases have begun to erode political support for "AIDS exceptionalism", reassessment and modification of this model has become a critical priority (see *Project Inform 1997; Stolberg 1997*).

In many respects, creation of HIV/AIDS employment services is a good place to begin this process. In the absence of a targeted Federal initiative, creation of these services will require access to new sources of funding and adaptation of service models originally developed to serve other populations. The Rehabilitation Act of 1973, as Amended, funds and mandates that state

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[2] As AIDS increasingly becomes a chronic, manageable disability for that segment of the affected population able to comply with the new treatment regimens, and promotion of consumer independence has become a central priority of AIDS advocacy, unprecedented opportunities for collaboration with the disability community have arisen *(see Vachon 1993, p. 205)*. Its model workplace entry and re-entry programs and policy proposals for the reform of federal, state and private insurance trial work programs are highly relevant to critical, emerging priorities of the AIDS community. This development has created opportunities for broad collaboration in federal and state policy, legislation and service delivery development, building upon the successful record of AIDS and disability advocates in working together at the federal level to secure passage of landmark civil rights and health care legislation. In particular, proposals developed by the National Council on Disability with respect to Social Security reform and promotion of consumer choice within state vocational rehabilitation agencies provide an excellent starting-point for the development of policy, legislative and service delivery agendas that will promote meaningful reform to meet the emerging employment needs of all people with disabilities. In developing its policy and services, the City might consider collaboration with the disability community in these areas: (a) development of strategy to ameliorate or eliminate the financial disincentives to employment faced by people with HIV/AIDS and other disabilities through reform of federal, state and private long-term disability policy; (b) coalition building on civil rights issues, e.g., the definition of what constitutes a disability under the Americans with Disabilities Act, that impact upon the employment interests of people with HIV/AIDS and other disabilities; and (c) promotion of consumer choice within the state vocational rehabilitation system.

rehabilitation agencies provide comprehensive, coordinated, effective, efficient and accountable vocational rehabilitation services for people with disabilities; and Congress, the Equal Employment Opportunity Commission and the courts have held that people who have or are perceived to have HIV infection meet the eligibility criteria for these services. Although few CARE-funded AIDS service delivery systems have so far forged effective linkages with their state vocational rehabilitation agency, which consumers have not yet begun to access in numbers proportionate to their eligibility, this clearly is one of the principal sources of federal funding that will be available nationally to respond to the emerging employment needs of people with HIV/AIDS.[3] The participation of two members of the California Department of Rehabilitation in the Subcommittee's planning process augurs well for the Department's cooperation with Mayor Brown's initiative to establish an HIV/AIDS employment service delivery system in San Francisco.

The City is fortunate that the emergence of employment as a significant consumer need coincides with the sweeping reorganization of San Francisco's employment development services necessitated by Congressional enactment of the Personal Responsibility and Work Act of 1996 *(P.L. 104-193)*. The work requirements and lifetime limits on the receipt of welfare mandated by this bill have resulted, in San Francisco, in plans to create a Workforce Development System centered upon one-stop Career Centers that may be expected to organize available resources far more efficiently than before. The purpose of the Workforce Development System, designed to serve all low-income San Franciscans, is "to link job creation activities to an array of high quality job readiness, skills training, job placement, retention, career advancement and supportive services designed to help new and incumbent workers function effectively in the workplace" *(San Francisco Department of Human Services 1997)*. The System includes job forecast capacity to ensure a "market-driven investment in training and strategically targeted job development", a first-source hire program that obligates companies doing

[3] According to a summary prepared for the Subcommittee by Steve Arcelona, other existing federal sources of funding in San Francisco for employment and job training, which can be accessed to meet the needs of people with HIV/AIDS provided that appropriate service models and system linkages are developed, include Job Training Partnership Act funds administered by the Private Industry Council: $2,197,483 for laid-off and long-term unemployed workers, and $2,241,379 for economically disadvantaged adults; Community Development Block Grant funds administered by the Mayor's Office of Community Development (MOCD): $1,756,515 in Public Service funding dedicated to employment and $1,078,327 in Economic Development funding; $1,316,988 in Housing and Urban Development (HUD) funds, also administered by MOCD; $5,247,619 in the HUD Supportive Housing Program administered by the Department of Human Services for homeless youth and adults; and an estimated $750,000 in Redevelopment Agency funding set aside for employment and training.

business with the City to recruit qualified low-income applicants for available jobs, the development of a "one stop" electronic information system (administered by the Private Industry Council) that provides job forecast data, current job listings and information about training and other services, and finally the creation of neighborhood-based Career Link Centers that provide access to a comprehensive array of employment-related resources as well as needed supportive services. In creating services to meet the employment needs of people with HIV/AIDS, it is critical to forge effective, working links between the CARE-funded AIDS service delivery system and the Workforce Development System devised as San Francisco's response to welfare reform.

As currently planned, the Workforce Development System does not include services designed to remove the specific, multiple barriers to employment faced by people with HIV/AIDS. To take advantage of the opportunities created by combination therapy to return several thousand previously disabled San Franciscans to productive employment, the City clearly needs to create new services designed to ameliorate or remove these barriers, while ensuring effective coordination between AIDS social services and the array of job counseling, training and placement services now organized into the Workforce Development System. Accordingly, and pursuant to Mayor Brown's direction in a discussion of options for service delivery system development in November 1997, the Subcommittee recommends creation of an HIV/AIDS Employment Development Unit in the Department of Public Health to provide core direct employment services (including assessment, limited benefits counseling, job counseling, retention and placement services), and to coordinate public and private resources in an integrated, consumer-centered system that emphasizes the effective and cost-efficient utilization of San Francisco's Workforce Development System and the California Department of Rehabilitation (see **section 5** for the rationale for locating these services within the Health Department).

Given the uncertainties with respect to the long-term efficacy of the new treatments as well as the fate of current federal and state efforts to remediate financial disincentives to employment for people with HIV/AIDS, the Subcommittee recommends that this Unit be created as a pilot project with staffing sufficient to serve 850 consumers annually, with a first-year success rate in permanent placement of at least 75%, and that it include strong planning and evaluation capacities to ensure appropriate adjustment for service levels as the epidemic continues to change. Placement of some 600 people with HIV/AIDS in permanent jobs during the program's first year of operation would increase the overall employment rate of people with AIDS nearly 50% and provide significant annual cost savings (for figures and assumptions, see *Kemp and Kahn 1998*).

In designing an employment service delivery system to meet the needs of the HIV-positive population of San Francisco, the Subcommittee has been guided by the goal of providing multiple points of access, consistent with consumers' existing institutional affiliations, to an integrated system that provides the broad range of services necessary for success in the workplace by a highly diverse population. Accordingly, while the new HIV/AIDS Employment Development Unit will provide direct employment services for consumers accustomed to receiving CARE-funded services, the Subcommittee recommends that other City Departments also provide enhanced HIV/AIDS services within their established programs -- most notably, the Department of Human Services for recipients of General Assistance and Temporary Aid to Needy Families, and the Human Rights Commission in its HIV in the Workplace technical assistance and complaint resolution program. The HIV/AIDS Employment Development Unit should maintain centralized tracking responsibilities for all HIV-positive San Franciscans seeking employment services through the City and its nonprofit contractors. To ensure quality control in a system with multiple points of access, the Unit should also set standards for assessment, service plan development, care coordination, monitoring of service receipt, evaluation and minimum professional qualifications for City-funded staff positions at nonprofit contractors that wish to invest resources to meet the needs of the various populations impacted by HIV/AIDS.

The establishment of HIV/AIDS direct employment services in the Department of Public Health represents one of thirty-seven recommendations developed by the Subcommittee to ensure that the City's response to the opportunities created by the new therapies is comprehensive, coordinated and cost-effective. These recommendations fall into six broad categories: the creation of an appropriate planning, evaluation, policy and management structure for the City's new HIV/AIDS employment services **(Recommendations 1-9);** service system delivery development, including linkage of employment with AIDS housing, homeless, emergency assistance, legal, psychosocial and other supportive services, and development of employment-related services for people with HIV/AIDS in other City Departments **(R1O-R24);** job identification and creation **(R25-R31);** legislation **(R32-R33);** evaluation and data collection **(R34-R35);** and marketing **(R36-R37).**

In the following pages, the Subcommittee has attempted to place these recommendations in context and explain their rationale through discussion of the scope, priorities and limitations of its planning process **(section 2),** a profile of consumers and barriers to their employment **(section 3),** the creation of an appropriate planning and policy structure for HIV/AIDS employment services **(section 4),** and finally the proposed establishment of

an HIV/AIDS employment service delivery system, including coordination with nonprofit HIV/AIDS employment and social service providers and the Workforce Development System **(section 5).** The Subcommittee's recommendations are set forth in summary form at the conclusion of this chapter and cross-referenced in the body of the text.

2. The Subcommittee's Planning Process: Scope, Priorities, Limitations

In structuring its planning process, the Subcommittee has made every effort to involve a broad range of stakeholders in its deliberations. The Subcommittee's membership includes several consumers of AIDS services as well as representatives from the small business and foundation communities, the Departments of Public Health and Human Services, the Private Industry Council, the California Department of Rehabilitation, and nonprofit AIDS social service and employment development providers. The Subcommittee has supplemented this expertise by taking oral or written testimony from numerous individuals (listed at the end of this Subcommittee Report), to whom thanks are due for providing information that played a material role in the Subcommittee's deliberations or in its formulation of recommendations.

To ensure appropriate opportunities for public input, the Subcommittee also held two widely-publicized Forums. The first, held in September 1997 for consumers, strongly impressed upon the Subcommittee the importance of effective linkages between employment, housing and psychosocial services proposed in **R14-R17.** At the second Forum, held in December 1997 for employers and vocational service providers, the Subcommittee presented its draft recommendations for public comment, strongly encouraging the submission of written testimony. A detailed response from the Life Employment Program of IAM CARES has resulted in the clarification or improvement of several recommendations; no other testimony was received. In addition to these public events, the Subcommittee Co-Chairs have held meetings with the staff of City Departments impacted by the Subcommittee's recommendations to solicit their input.

In keeping with its broad charge from the Mayor's Office, the Subcommittee has taken care to ensure that its recommendations provide:

- people with HIV/AIDS entering the workplace for the first time, as well as those re-entering it, have access to job training and other services necessary to place them in permanent positions; and

- that people who are HIV-positive, but not eligible for AIDS disability, also have access to services that will assist them in securing or maintaining successful employment.

Early in its deliberations, the Subcommittee recognized that these planning objectives could be achieved only through the development of recommendations to create system linkages that ensure that both groups access to the existing employment development resources in San Francisco. In the absence of a federal initiative that provides significant new dollars earmarked for HIV/AIDS employment, and given the City's financial interest in moving people with HIV/AIDS on disability into employment with health insurance, the City is likely to prioritize investment in those for whom this investment has the greatest fiscal return. At the same time, however, the City has an obligation to ensure that HIV-positive people, or people with HIV/AIDS entering the workforce for the first time, are not discriminated against in the allocation of its existing employment development funding (see above, note 3).

The Subcommittee's attempts to assess the City's current level of services to these two groups have been stymied by the failure of any City Department or agency (except the Human Rights Commission) to track the delivery of employment services to people with HIV/AIDS. The absence of this information makes it impossible to determine how effectively existing programs serve this population or its subgroups. Accordingly, the Subcommittee attaches great importance to **R18,** which recommends that the Mayor require all City departments, agencies and affiliated entities that provide or fund direct services to develop mechanisms to identify and track self-identified HIV-positive consumers (preferably through an anonymous coded identifier), conduct a formal assessment of their social service and employment needs, and prepare a specific Action Plan for the Mayor's review and approval to assure provision of service in proportion to the overall population eligible for these services. The Subcommittee has also developed recommendations designed to ensure that the Department of Human Services, the Private Industry Council, Mayor's Office of Community Development, the Redevelopment Agency and other City Departments develop appropriate, HIV/AIDS-specific services within their established programs **(R15-R24).** Assignment of centralized tracking responsibilities for all HIV-positive San Franciscans seeking employment services through the City and its nonprofit contractors to the new HIV/AIDS Employment Development Unit will help to ensure achievement of this objective.

In assessing system-wide consumer needs, the Subcommittee has also encountered significant limitations in existing data which should be acknowledged to underscore the need for further research to guide program planning, implementation and evaluation.

The first limitation is well-known: HIV prevalence rates in San Francisco are set through an annual consensus meeting of local experts and scientists rather than through surveillance by the San Francisco AIDS Office, so that considerably less is known about the specific characteristics of the 15,000 people in San Francisco (2.1% of the total population) estimated by the May 1997 conference to be HIV-positive than about the 7,963 who have been diagnosed as living with AIDS through December 31, 1997.

The second limitation is more serious from the perspective of system-wide service development and prioritization of resources: currently, the AIDS Office does not include employment as a service category in its annual assessment of consumer needs, limiting this survey to services funded under the CARE Act. As a result, there are no comparative measures of consumer employment needs comparable to those established for the twenty-one categories surveyed in 1996 (which include, e.g., acupuncture/herbs, childcare/summer camp, foster care/adoption and translation). Since the four-month planning period afforded the Subcommittee did not permit the development, distribution and analysis of a new survey instrument specifically tailored to its planning purposes, it has had to supplement the limited available information by analysis of a broad range of relevant local, state and national material compiled in a *Briefing Book* more than seven hundred pages in length.[4] While the Subcommittee has made due allowance for limitations in available data in developing its recommendations, it strongly recommends that the Department of Public Health prioritize data development as it assumes responsibility for the delivery of services in this area during 1998 **(R34-R35).**

Other initiatives developed in the course of the Subcommittee's planning process include the Co-Chairs' proposal for creation of the Mayor's AIDS Leadership Forum to strengthen the planning capacities of the more than one hundred agencies delivering AIDS services in San Francisco, and

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[4] For information on consumer employment needs in San Francisco, the Subcommittee has relied upon an extensive 1996 survey of 390 consumers (21.5% response rate) conducted by the interim Board of Directors of Positive Resource and a June 1997 survey of 1,000 HIV-positive gay men (12.5% response rate) by AIDS Benefits Counselors (only partial results from which were made available to the Subcommittee), and it has carefully compared their results with available national and regional data, most notably the careful study (based upon 1991-92 data) of the diagnostic history of people living with HIV and its relation to function, disability and labor force participation over time by *Sebesta and LaPlante 1996*, the excellent "Back-to-Work Survey" conducted by the Northwest AIDS Foundation in March 1997 and the results of three focus groups conducted by AIDS Project Los Angeles (*Los Angeles, 1997*).

Jim McBride's proposal for a City-wide media campaign -- in connection with the establishment of an HIV/AIDS Employment Development Unit in the Department of Public Health -- to increase awareness of and access to the resources that will help people with HIV/AIDS succeed in the workplace. Mayor Brown has approved both proposals for implementation during Spring, 1998.

Finally, consistent with its charge, the Subcommittee has focused on local planning and policy issues, recommending the City's support of several state and federal policy initiatives, but making no attempt to address them in a comprehensive way.[5]

3. Profile of Consumer Needs and Barriers to their Employment

In designing San Francisco's HIV/AIDS employment delivery system, two factors are critical: the size of the consumer population, which informs decision-making concerning the system's capacity; and the range of employment barriers faced by people with HIV/AIDS, which informs the kinds, number and coordination of services necessary to secure successful results. The findings reported here have significantly informed the recommendations reported in **section 5** below concerning service delivery system development.

As indicated above, the baseline employment figure for people with AIDS in San Francisco is 17% (9% full-time, 8% part-time), based upon an AIDS Office self-administered questionnaire completed by 767 consumers of CARE-funded services (representing a 28% response rate) during August and September 1996.[6] A variety of more informal indices indicate that system-

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[5] Proposals for federal reform were developed in a meeting on "Returning to work with HIV/AIDS: Public Policy Roundtable", held in New York on 21-22 July 1997. The status of their implementation and related federal and state policy initiatives will be discussed at a Forum sponsored by the Subcommittee for Mayor Riordan's Los Angeles Task Force on Employment Issues for People with AIDS and other AIDS policy advocates on January 28, 1998.

[6] See *Vachon 1993, pp. 206-09, 217* and *Sebasta and LaPlante 1996* for a summary of national data on the relationship between disease progression, development of functional limitations and employment status of HIV-positive people. Prior to the onset of symptoms, their employment rates are comparable to that of the uninfected population; by the end of the first year following the onset of symptoms, a third to half have left the workforce due to health impairments and various barriers and disincentives to maintaining employment, discussed below. The Subcommittee recommends that the Department of Public Health undertake a re-examination of these findings through a study of the impact of the new

wide demand for employment services has climbed steadily since the time of that survey[7], although no figures based on a sample comparable to that of the 1996 AIDS Office questionaire are available to indicate the extent to which the employment rate of people with HIV/AIDS has increased over the past sixteen months[8].

Even if such figures were available, however, they would not provide a good indication of anticipated system demand for workplace services: all available local and national survey data indicates that many people with HIV/AIDS on disability who are planning, hoping or considering employment are held back from doing so by concern about the long-term efficacy of the new therapies and by the financial disincentives, discussed below, that many people with HIV/AIDS face in moving from disability to employment (see, e.g., *Vachon 1993, pp. 209-212; Positive Resource 1996 and 1997; Seattle 1997; Los Angeles 1997; Atlanta 1997*). The passage of bills pending in the California Legislature and in Congress, by ameliorating or eliminating these disincentives, could have a major impact virtually overnight in stimulating consumer demand for these services. In California, Assemblywoman Carole Migden has re-introduced successor legislation to AB 1099 (which passed 77-0 in the 1997 Assembly but was vetoed by Governor Wilson) that provides relief from MediCal share of cost requirements for people with HIV/AIDS and other disabilities who return to the workforce; while in Congress, legislation is pending, based upon proposals developed by the National Council on Disability, that would reform Social Security trial work regulations and broaden consumer choice in utilization of vocational rehabilitation resources.

Accordingly, current levels of consumer demand for HIV/AIDS employment services may be expected to rise during 1998, as reform of federal, state and private disability and health insurance begins to remove financial disincentives to employment that are costly to payors as well as the disabled. Current indicators with respect to the efficacy of antiretroviral combination therapy, it might be added, are highly favorable (see, most

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therapies on the relationship between disease progression, development of functional limitations and employment status in the MV-positive population of San Francisco **(R34).**

[7] As *Kreiger 1997* notes, the decline in AIDS mortality coincides with growing evidence that the increased longevity of people with HIV/AIDS, many of them chronically ill, is placing severe stress on some HIV/AIDS social services -- including benefits counseling and employment programs, featured in *Layne 1997* and *Laird 1997.*

[8] The 1996 Positive Resource survey indicated an employment rate of 12% and the 1997 survey an employment rate of 32% (10% full-time, 13% part-time and 9% self-employed) -- which may indicate significant real increases in the employment rate in at least that part of population served by this program.

recently, the 60% drop in AIDS deaths in California during the first six months of 1997 reported by *Russell 1998*). It is also likely that creation of HIV/AIDS employment services fully responsive to consumer need will increase both interest in and utilization of these services. As the Department of Public Health begins to provide HIV/AIDS employment services, its program planning should incorporate a strong data collection and evaluation component to monitor trends in service demand and utilization related to these environmental factors.

The best current evidence of potential consumer demand for employment services is provided by the careful, March 1997 survey of 251 people with AIDS (139 responses, a 55% rate) conducted by the Northwest AIDS Seattle Foundation, which found 60% hoping or planning to return to work, 31% not, 7% unsure and 2% currently working (see also *Atlanta 1997*). While the demography of the AIDS epidemic in Seattle differs from that in San Francisco (for which the best overview remains *Planning Council 1995, pp. 19-25*, as supplemented by the AIDS Office's quarterly Surveillance reports), we arrive at a similar figure based upon the percentage of system-wide usage of the new antiretroviral therapies in San Francisco. Although the long-term failure rate of these therapies remains to be established, with the current, published data fluctuating significantly, this is probably the best available basis on which to estimate system-wide potential for consumer utilization of employment services.[9]

Usage of antiretroviral therapy in San Francisco is high. Preliminary findings from the San Francisco sample of the Gay Urban Men's Study, based upon a sample of 864 men who have sex with men, indicate that among those who are HIV-positive, 24% were not on any type of antiretroviral treatment, 2% reported only protease inhibitor treatment, 22% reported other antiretroviral use, and 52 % reported use of both protease inhibitors and other antiretrovirals.[10] Even higher utilization of the new therapies is indicated by the San Francisco AIDS Office's chart reviews of the 675 AIDS cases reported in 1997, 482 (71%) of which indicated usage of

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[9] When adjusted, of course, to take into account failure rates and such factors as genetic defects which impair disease progression in some parts of the population.

[10] These are unweighted, preliminary findings, kindly made available to the Subcommittee by Joseph A. Catania, Ph.D., Department of Medicine and Center for AIDS Prevention Studies, Urdversity of California, San Francisco. The survey, conducted in 1997-98 in San Francisco, New York, Chicago and Los Angeles, is a random probability sample of men who have sex with men (MSM) aged 18 and older. The sample represents approximately 90% of all estimated MSM households in each of those cities. For San Francisco we obtained a sample of 846 MSMs interviewed by telephone, approximately 22% of whom reported being HIV-positive (self-reports were confirmed for a random sub-sample of men by HIV antibody testing using oral collection kits).

protease inhibitors. While no study has yet been conducted to measure the impact of combination antiretroviral therapy upon the relationship between disease progression, functional limitation and employment status reported by *Sebasta and LaPlante 1996* (based on the 1991-92 AIDS Cost and Services Utilization Survey), such high utilization of the new therapies is likely to stimulate long-term demand for the kinds of services that help people with HIV/AIDS maintain their independence and quality of life, employment services included.

Among consumers in San Francisco currently seeking employment, the best evidence comes from the 1996 Positive Resource survey of 390 consumers, 84 of whom responded (21.5%), with the following results:

- All respondents were HIV-positive, 52% with an AIDS diagnosis; 29% stated that they were in recovery, on average for 4.15 years.
- *Gender:* 91% male, 5% female and 4% transgendered; *sexual orientation:* 85% gay, 4% bisexual, 4% heterosexual and 7% declined to state; *race:* 72% Caucasian, 2% Asian/Pacific Islander, 11% African American, 6% Latino/a, 6% declined to state, and 2% mixed race or other[11]; 93% reported English as their primary language. *Age:* 79% of respondents were between 30 and 44, averaging 39.5; *average household size* was 2.15; 4% female heads of household.
- *Income:* 12% were working at the time they completed the survey; 45% were receiving federal or state government disability benefits (12% SSL 24% SSDI, 9% SDI); 9% County GA; **29% reported no income.** The 64 consumers reporting income averaged $1,119 from all sources.
- *Work preference:* 62% preferred part-time to full-time employment; 58% sought permanent rather than temporary employment.

The survey also asked consumers to assess the usefulness of twelve existing or possible rehabilitation services as a guide to program assessment and planning.

People with HIV/AIDS who seek to enter or re-enter the workforce face barriers and financial disincentives similar to those which the disabled have experienced for decades (see, e.g., *Vachon 1993; Hamilton 1997; National Council on Disability 1997*). Since the Social Security Administration defines disability as an "inability to work", gainful employment tends to be

[11] The racial distribution of respondents is less diverse than that of Positive Resource consumers as a whole: in 1996, 67% of consumers were Caucasian, 2% Asian/Pacific Islander, 14% African-American, 12% Latino, 3% Native American.

treated as evidence that the disability, and hence the need for supportive services, no longer exists. This problem is most evident in "The Cliff" (the abrupt termination of any SSI and SSDI benefits at critical earning levels as low as $500 in any nine months over a five-year period), the "negative income" that tends to result from the withdrawal of supportive services, including health care, for all but those capable of maintaining relatively well-compensated employment, and in the complexity of the existing trial work programs. Private long-term disability insurance, when available, also tends to contain financial disincentives to employment because of inadequate recurrent disability provisions, which would assure people of continuing support if the disability recurred (as is frequently the case with HIV disease), and inadequate residual provisions, which would enable someone to maintain part-time employment while retaining some long-term disability coverage.

Accordingly, although it is in the financial interest of all concerned for people disabled by HIV/AIDS to return to work, many face permanent loss of the insurance coverage that pays for their medical treatment if they accept even part-time employment, and all must negotiate complicated regulations to preserve their rights to future benefits in the event their disability recurs (see, e.g., *Anders 1997*). Removal of these disincentives to employment will require significant changes in federal, state and private disability insurance policies. Until legislative reform succeeds, people with HIV/AIDS on disability will continue to require extensive benefits counseling and legal advocacy services to remove or mitigate the financial disincentives they face in considering workplace entry or re-entry.

In addition to potential loss of health and disability benefits, people with HIV/AIDS face a variety of other barriers to employment more directly related to their HIV status. These barriers include discrimination on the basis of HIV status or sexual orientation in employment decisions; extended absences from the workplace that tend to render skills obsolete and to sever ties with informal networks that are a critical source of job leads; the need to find employment suitable to the demands of managing HIV disease, which leads many re-entry candidates to prefer a job different than that which they left as a result of AIDS disability; and the need for a broad range of psychosocial services to handle the multiple stresses associated with managing their disability within the workplace. The absence of stable housing, a major problem for people with HIV/AIDS in San Francisco, is a barrier which makes it virtually impossible to secure and maintain stable employment.

In addition to these barriers, increasing numbers of people with HIV/AIDS come from low-income backgrounds and have limited education or

employment experience. For these individuals, access to job-readiness and training programs is critical in equipping them to secure and maintain permanent employment. Accordingly, special care in designing the HIV/AIDS employment service system outlined in **section 5** below has been taken to ensure close coordination with the broad range of employment development services organized into the Workforce Development System. Indeed, inasmuch as surveys consistently show that a high percentage of people with HIV/AIDS do not wish to return to their previous job or career, access to such services may be as important for highly skilled people returning to the workforce after an extended absence due to disability as it is for those entering it for the first time.

4. Creation of a Planning, Evaluation, Policy and Management Structure for the HIV/AIDS Employment Service Delivery System

During the past year, despite community requests and extensive national publicity on consumers' emerging employment needs, neither the Department of Public Health nor the Mayor's HIV Health Services Planning Council has taken action to assess these needs locally, develop measures to prioritize their importance in relation to other areas of unmet need or establish a planning process to study the issues involved in the development of appropriate services. The Council's decision not to include these services in its planning activities may be explained partly by the limitation of its jurisdiction to the prioritization of CARE funding and certain ambiguities, discussed below, concerning the eligibility of employment services for this funding. In any case, creation of an effective HIV/AIDS employment service delivery system clearly requires some modification of the City's existing AIDS planning, evaluation, policy and management structure to make it more responsive to consumers' changing social service needs and to develop the necessary system links between this structure and that responsible for San Francisco's employment development resources.

In taking testimony from City officials, the Subcommittee found that no Department and no existing planning or oversight body currently considers itself responsible for the development, coordination, funding and oversight of HIV/ AIDS employment services. Accordingly, the Subcommittee urges the Mayor to designate a Department-Head level employee who will be accountable for the implementation of approved Subcommittee recommendations and for the effective operation and coordination, across Departmental lines, of San Francisco's HIV/AIDS employment services **(R1).** The Subcommittee also recommends that the Mayor appoint this employee,

or the Director of the new HIV/AIDS Employment Development Unit, to the Workforce Development Steering Committee to ensure representation of the interests of people with HIV/AIDS in city-wide employment development planning **(R3).**

Equally critical is the creation of a community planning body to provide planning, evaluation and policy oversight of HIV/AIDS employment services, with the necessary budgetary authority to set priorities within the various funding streams assigned by the Mayor to support these services **(R2).** The creation of an HIV/AIDS Employment Development Committee of the Health Commission, its membership appointed by the Mayor, would fit neatly into the City's existing planning and policy structure for health services. In addition to its experience in managing complex community planning processes involving extensive collaboration across disciplinary and departmental lines, the Health Commission already has the necessary budgetary authority to ensure programmatic implementation of established planning priorities within the Department of Public Health.

To promote effective fiscal planning and fund allocation decisions by planning bodies which oversee funding for which HIV/AIDS employment services are eligible, the Subcommittee also recommends the appointment of members of the HIV/AIDS Employment Development Committee to the Private Industry Council, Mayor's Office of Community Development's Citizens' Committee on Community Development and the Planning Council **(R4-6).**

In addition to these measures to create an appropriate institutional framework for planning, evaluation, policy and management of HIV/AIDS employment services, the Subcommittee also recommends that the Mayor direct the Planning Council to clarify two specific policy issues involving the administration of CARE funding: the first is important to ensure development of appropriate system linkages between CARE-funded AIDS social services and the California Department of Rehabilitation, and the second to remove a potential financial disincentive to employment among people with HIV/AIDS arising from current policy with respect to eligibility for CARE-funded services.

1. As indicated above, the City has not moved more quickly to develop HIV/AIDS employment services in part because these services have been assumed to be ineligible for CARE funding and therefore excluded from the planning and management oversight of the Planning Council and AIDS Office. Recent clarification of policy concerning the use of CARE funds to support employment-related services provides an opportunity on which the City may wish to capitalize in developing strategy to enable consumers of care to access, in numbers more appropriate to their eligibility, the resources

of the California Department of Rehabilitation, which is funded and legally mandated by the Federal Government to provide employment services for people with disabilities, including those with HIV/AIDS.

On February 1, 1997, the Department of Health and Human Services, Division of HIV Services, issued Program Policy Notice No. 97-02.17, which states that "Funds awarded under Title I and II of the CARE Act **should not**[12] be used to support employment, vocational rehabilitation, or employment-readiness services." The intent of this policy has been clarified in a letter released on July 1, 1997 by Anita Eichler, Director of the Division of HIV Services, which explains that "this disallowance stems from the fact that such services are required to be provided by designated state agencies with the assistance of Federal funding to operate a comprehensive, coordinated, effective, efficient, and accountable program of vocational rehabilitation *for individuals with disabilities"*, which category includes people with HIV/AIDS. The letter encourages CARE Act Programs to refer consumers of care to state compensation programs that are mandated to provide these services, and provides a one-page "Resource List" to facilitate their identification.

The July 1, 1997 policy clarification represents an application of the principle set forth in the CARE Act that "funds received ... will not be used to make payments for any item or service to the extent that payment has been made, or can reasonably be expected to be made" by other sources of funding *(P.L. 101-381, stat. 583; revised as P.L. 104-146).* In "Allowable Uses of Funds for Discretely Defined Categories of Services" *(Program Policy Notice No. 97.02 [issued February 1, 1997], page 2)*, this principle is interpreted to require that grantees or their subcontractors make "reasonable efforts" to secure other funding instead of CARE Act funds whenever possible: "it is an appropriate use of CARE Act funds to provide case management or other services which have as a central function ensuring that eligibility for other funding sources (e.g., Medicaid or Medicare, other local or State-funded HIV/AIDS programs, or private sector funding, etc.) is aggressively and consistently pursued." Anita Eichler's July 1, 1997 policy clarification essentially adds state vocational rehabilitation resources to the list of examples set forth in the parenthesis.

Accordingly, while direct "employment, vocational rehabilitation, and employment readiness services" cannot currently be funded under the CARE Act, it is clear that outreach, information and referral and case management services that link consumers in the CARE-funded system to these services

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[12] The Department's typography to designate "definitive program guidance". For an example of utilization of Ryan White CARE Title II funds used to support HIV/AIDS employment services, see *Vachon (1993), p. 216.*

are eligible for CARE Act funds. Case management is explicitly cited as an allowable expense in Program Policy Notice No. 97.02, as quoted above. Eligibility of outreach services for Title I and II CARE Act funds is now governed by Public Policy Notice No. 97.03 (issued March 31, 1997), which states that "CARE Act funds may also be used for outreach through directories of services and similar resources to aide *[sic]* consumers in making the most effective use of available services." While Ms. Eichler's July 1, 1997 letter does not discuss the appropriate mechanism to "refer" CARE Act consumers to state vocational rehabilitation agencies, these Program Policies provide warrant for funding outreach, information and referral and case management services that provide consumers of CARE-funded services access to employment-related services funded through other sources.

For the reasons explained in **section 1** above, the development of appropriate system linkages between the CARE-funded AIDS service delivery system and the California Department of Rehabilitation is critical to ensure that people with HIV/AIDS have access to the resources specifically allocated by the federal government to support employment services for people with disabilities.[13] Accordingly, the Subcommittee recommends that the Mayor direct the Planning Council to seek clarification from the U.S. Department of Health and Human Services concerning the eligibility for funding under the Ryan White CARE Act of case coordination and information and referral services that link consumers of the CARE-funded AIDS service delivery system with the resources of the state Department of Rehabilitation. If this policy clarification is affirmative, the Planning Council should consider funding such services to increase the overall resources available for people with HIV/AIDS in San Francisco and to facilitate the redirection of CARE funds to the most severely disabled **(R7).**

2. Although the CARE Act legislation provides that HIV health care and support services be provided without regard "to the ability of the individual to pay for such services; ... in a setting that is accessible to low-income individuals with HIV disease" and that "a program of outreach will be provided to low-income individuals with HIV disease to inform such individuals of such services" *(P.L. 104-381, stat. 583)*, nothing in the legislation appears to prescribe or prohibit restriction of eligibility for CARE-

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[13] The mere establishment of referral and system linkages will not suffice to meet the employment-related needs of the HIV-positive population of San Francisco (e.g., the Department of Rehabilitation's Order of Selection criteria can exclude those who are less functionally impaired from services), but it would represent a step in the right direction, bringing some additional resources into play and freeing up others.

funded services to the disadvantaged. In San Francisco, however, the Planning Council in recent years has increasingly targeted this funding by economic status, race, sex and IV drug use status: typical Department of Public Health contract language identifies the target population for services as "people with HIV in San Francisco, especially those with low income (defined as $15,000 per year or less), women, people of color, and injection drug users," who are in need of the contracted service. In some service areas, this language is used as warrant for excluding from eligibility for services people who do not fall into the categories enumerated in the second clause.

The Subcommittee is concerned that San Francisco not reproduce locally the systemic disincentives to employment embodied in state and local policy. Accordingly, since the application of an income-based means test for receipt of CARE-funded services (particularly at the level quoted above) could effectively deprive a recently employed person of access to critical HIV health and support services necessary to maintain employment, the Subcommittee recommends a review of the requirements of Federal legislation *(P.L. 101-381, 104-146)*, existing Planning Council policies and current contract language in order to develop and adopt consistent policies and procedures, with respect to continued utilization of CARE-funded services by consumers who have entered or re-entered the workplace. These policies should provide HIV-positive employees without health insurance, whose income from employment might nominally render them ineligible for CARE-funded services, continued access to such services for a transitional period, and insured employees a transitional period not shorter in duration than any pre-existing exclusion clause in their insurance **(R8).**

Implementation of the recommendations set forth in this section will help to rectify institutional barriers to the development of effective HIV/AIDS employment services in San Francisco, while creating a planning, evaluation, policy and management oversight structure capable of coordinating the broad range of resources necessary to meet consumers' employment service needs.

5. Development of San Francisco's HIV/AIDS Employment Service System

In designing an HIV/AIDS employment service delivery system responsive to the variety of needs and workforce barriers summarized in **section 3** above, the Subcommittee has been guided by the following principles:

- Multiple points of access, consistent with consumers' existing institutional affiliations, to an integrated system that provides the

broad range of services necessary for success in the workplace by a highly diverse population;

- Efficient coordination of consumer access to resources across systems and funding streams, including the resources available through the Workforce Development System, the California Department of Rehabilitation, the San Francisco Human Rights Commission, and other public and nonprofit services; and
- System-wide standards of quality control in the provision of services, including standards for assessment, service plan development, care coordination, monitoring of service receipt, evaluation and minimum professional qualifications for City-funded staff positions at nonprofit contractors, with strong, centralized tracking capabilities to assist in program planning, monitoring and evaluation.

These principles have been developed in response to the circumstances set forth in the **Introduction**: that in the absence of new funding specifically designated for HIV/AIDS employment services, service system development should focus on securing and coordinating consumer access to programs and funding originally developed for other populations, while providing the additional supportive services necessary to assist with specifically HIV-related needs.

In creating its HIV/AIDS employment service delivery system, the City is fortunate to be able to build upon several existing programs that provide some of the resources needed by people with HIV and AIDS to secure and maintain successful employment. Currently, two nonprofit programs in San Francisco, in addition to the state Department of Rehabilitation, provide employment placement services for people with HIV/AIDS, while other programs provide benefits counseling, legal advocacy, employment discrimination complaint resolution, and workplace technical assistance services that are essential components in a comprehensive continuum of HIV/AIDS employment services. An inventory of these resources may prove helpful to the reader in understanding the Subcommittee's rationale for the creation of an HIV/AIDS Employment Development Unit in the Department of Public Health to increase overall system capacity and to integrate available resources in an effective, efficient and coordinated system.

Positive Resource is an employment program founded in 1992, and since November 1996 affiliated with **AIDS Benefits Counselors**, whose mission is to empower persons living with HIV/AIDS to maintain their independence and quality of life through employment, thereby enhancing their own mental, physical and financial health while remaining productive, engaged members of the community. Its services include employment counseling and placement, support groups and seminars designed to equip

people with HIV and AIDS with a better understanding of their legal rights and responsibilities concerning benefits and employment. Last year, Positive Resource registered 387 job candidates and made the following placements: 306 temporary, part-time jobs; 66 temporary, full-time jobs; 73 permanent, part-time jobs; and 26 permanent, full-time jobs.

The LIFE Employment Program of IAM CARES (International Association of Machinists' Center for Administering Rehabilitation and Employment Services) is a three-year, $660,000 federal demonstration project, funded by the Rehabilitative Services Administration, that begun operation in San Francisco in January 1997. The LIFE Employment Program has three objectives: to assist people with HIV/AIDS in securing and maintaining employment through provision of permanent placement and job retention services, particularly in the Federal Enterprise Community zones of the Mission, Bayview-Hunters Point, Visitacion Valley and South of Market; to educate and provide technical assistance to employers about HIV workplace issues; and to contribute to the AIDS services field by demonstrating how employment services may be provided to HIV or AIDS-affected populations. Last year, the LIFE Employment Program registered 133 job candidates, made 54 permanent job placements, and assisted 20 additional candidates in retaining employment through procurement of a reasonable accommodation.

The California Department of Rehabilitation has as its mission to assist people with disabilities (including those with HIV/AIDS), emphasizing those with the most severe disabilities, toward informed choice and success in education, vocational training, career opportunities, independent living and in the use of assistive technology to improve their employment opportunities and their lives. The Department provides eligible candidates an extremely broad range of services that include vocational counseling, training, placement and education, medical services and equipment, job-seeking skills training, on-the-job training, and assistance with transportation, telecommunications, equipment and related needs. The Department's San Francisco District Office, among the first vocational rehabilitation program in the country to provide HIV/AIDS-specific services, last year made an estimated 25 permanent placements. The Department is currently providing services to about 200 additional people with HIV/AIDS who may be expected to secure permanent employment upon the completion of their service plan.

Three other programs deserve mention as part of this inventory of the City's available employment-related resources for people with HIV/AIDS:

The San Francisco Human Rights Commission's HIV in the Workplace Technical Assistance Project, formally organized in 1994, aims to reduce acts of discrimination based on HIV/AIDS status that arise in

employment, public accommodation and housing in order to increase the productivity and longevity of people with HIV/AIDS, to maximize their access to services and businesses, and to ensure safe and secure housing. To achieve these objectives, the Project facilitates the mediation of complaints of HIV/AIDS-based discrimination through complaint resolution services that include assessment, interview, complaint and other document drafting, negotiation with complainant and respondent, investigation and witness interviews, mediation and consultation with people with HIV/AIDS regarding their employment and other rights. The Project also provides technical assistance to people with HIV/AIDS, employers, service providers, business owners and housing providers on how to comply with anti-discrimination laws, how to negotiate reasonable accommodation and how to effectively address the impact of HIV/AIDS.

The Benefits Counseling Program of AIDS Benefits Counselors, originally founded in 1987, provides no-cost access at sites in the Castro, Tenderloin and Mission districts to individualized, professional benefits analysis, advocacy and counseling about private, employment benefits and public benefits and entitlements such as long-term disability plans, health and life insurance, Social Security and MediCal; representation by staff attorneys before administrative law judges for consumers who require reconsideration of disability denials; and trainings and consultation with HIV service providers throughout Northern and Central California about benefits, entitlements and insurance programs. The program now provides drop-in groups focusing specifically on benefits issues related to employment.

The AIDS Legal Referral Panel, founded by volunteer attorneys in 1983, serves the civil legal needs of low and moderate-income San Franciscans with HIV through a broad range of services provided by staff and volunteer attorneys in such areas as insurance, housing, public and private benefits, child guardianship, debtor relief and employment discrimination. The agency's public policy program actively advocates for the reform of public and private insurance policies to remove financial disincentives and promote employment on the part of people with HIV/AIDS who wish to work.

The integration of these services, which are essential in meeting the employment needs of the HIV-positive population of San Francisco, into an effective, efficient and coordinated system poses several challenges.

In the first place, overall system placement capacity remains quite small in relation to the eligible consumer population: the existing services made fewer than 200 permanent placements during 1997, far less than the number of candidates seeking such employment. Accordingly, a significant increase in the resources currently dedicated to core direct employment

services is clearly necessary if the City is to take advantage of the opportunities afforded by the new therapies to move a significant portion of the HIV-positive population now on disability into productive employment. Investment in services focused on moving consumers into permanent jobs with health insurance clearly promises the greatest return for the City.

The vast majority of Positive Resource's placements are temporary, part-time jobs that either pay cash wages or merely supplement existing benefits. In fact, the 1997 Positive Resource survey shows that only 15% of the program's placements include health insurance. While supplemental or transitional work placements have a role in helping consumers on disability prepare for permanent employment, this is clearly not the model the City needs to follow if it is to make a significant, long-term difference in improving the independence and self-sufficiency of people living with HIV/AIDS. The Life Employment Program, on the other hand, which is required by its funding to focus on permanent placements, reports that 60% of these placements include health insurance – a promising indicator of the benefits to be obtained by investment in a service model with this focus. Now in its second year, this program is currently seeking funding to continue operation after expiration of its three-year federal grant.

As indicated above, the effective coordination of resources across City department, systems and funding streams is essential to the development of a working HIV/AIDS employment service system. For this reason, the Subcommittee recommends the creation of an HIV/AIDS Employment Development Unit in the Department of Public Health rather than investment of new resources in existing nonprofit programs. The two nonprofit HIV/AIDS employment programs do not have a record of collaboration (thus they operated throughout 1997 without a memorandum of understanding to specify areas in which to coordinate services or reduce duplication); neither has developed formal linkages to the new Workforce Development System, access to which is essential to provide job training resources for people with HIV/AIDS; and neither has the managerial resources necessary to plan, implement, monitor and evaluate program and system development that requires coordination among multiple government agencies.

As the Department of Public Health's experience shows, contracting out a new program requiring coordination among several government service providers to a nonprofit contractor can create insurmountable problems. In the case of the SSI/GA program, for example, the Department found it necessary to take the program back from the nonprofit contractor because of problems in the coordination of resources across multiple agencies. The creation of an HIV/AIDS employment service system is likely to pose even greater challenges of coordination across departments, service systems and

funding streams, and should not be jeopardized by investment of the City's resources in agencies that lack the managerial capacity to handle these challenges.

Accordingly, the Subcommittee recommends the establishment of an HIV/AIDS Employment Development Unit in the Department of Public Health, with these functions **(R10):**

- To provide core direct HIV/AIDS employment services, including assessment, limited benefits counseling, job counseling, retention and placement services;
- To oversee the provision of existing HIV/AIDS employment services provided by City-funded contractors, and to coordinate access to related services (e.g., financial assistance, client and legal advocacy, and psychosocial services) through referral to nonprofit contractors;
- To coordinate job training and placement through San Francisco's Workforce Development System, outstationing staff at the City's "one-stop" Career Centers in development;
- To link consumers of CARE-funded AIDS social services with the resources available through the California vocational rehabilitation system; and
- To plan, monitor, track and evaluate the quality of employment services for people with HIV/AIDS on a system-wide basis, including consumers served by the Department of Human Services, the Private Industry Council, the San Francisco Human Rights Commission and other City departments, agencies, affiliated entities and nonprofit contractors.

If implemented as recommended, this Unit will provide people with HIV/AIDS access to comprehensive assistance in surmounting systemic barriers to employment, while maximizing utilization of the City's existing employment development resources.

Related recommendations in the area of service delivery system development include provision for technical assistance to assist nonprofit agencies in working effectively together to deliver HIV/AIDS employment services **(R11)**, development of a collaborative training program to increase the effectiveness of AIDS service organization case managers and of vocational counseling and training staff in responding to the unique employment-related needs of people with HIV/AIDS **(R12)**, and revision of the Department of Public Health's standards of case management to include vocational rehabilitation as a required competence **(R13)**.

Testimony taken by the Subcommittee at its public forums underscores the importance of several modifications in the delivery of existing AIDS social services to meet the needs of consumers who seek to retain or secure employment. First, consumers identify stable housing as critical to success in the workplace. Accordingly, the Subcommittee recommends several measures to link employment with housing services, to review the policies, procedures and scheduled hours of homeless shelters, city clinics and AIDS service agencies to accommodate consumers' reasonable schedules, and to provide HIV-positive consumers who are homeless or at risk of homelessness with appropriate support, to increase their capacity to stabilize their lives through employment **(R14-R16)**.

Second, consumers also identify the lack of pyschosocial support services focused on workplace issues as a significant barrier to employment. Accordingly, the Subcommittee recommends review and modification of existing CARE and General Fund contracts to establish a continuum of psychosocial support services directly focused on workplace issues and coordinated with employment services at initial intake and assessment **(R17)**.

Consistent with the principle of encouraging multiple points of access into the HIV/AIDS employment service system, much of the Subcommittee's work has been dedicated to development of recommendations to ensure that consumers served by different City agencies experience reasonable uniformity in the quality of services provided, regardless of the point of entry into the system. Most consumers who enter the system outside the Department of Public Health are recipients of General Assistance and Temporary Assistance to Needy Families served by the Department of Human Services. Although significant numbers of these populations are known to be HIV-positive, the Department of Human Services has not hitherto identified, tracked or provided HIV-specific services for them, nor does it have formally constituted links to the AIDS service delivery system. The Subcommittee commends the Department of Human Services, however, for its stated intent to develop appropriate HIV-specific services within the context of its transformation of General Assistance and Temporary Assistance to Needy Families into employment development programs.

To achieve this goal, the Subcommittee recommends that the Department of Public Health work in concert with the Department of Human Services to identify the social service needs of the latter's HIV-positive consumers, to develop system linkages to ensure their access to existing CARE-funded services, and to assist in the planning and implementation of such additional services as are needed by the Department of Human Services' HIV-positive consumers **(R19)**. The Subcommittee also recommends that the Department of Human Services follow through on an

internal proposal to establish an HIV unit accountable for the identification, tracking, delivery and evaluation of services for people with HIV/AIDS, including those with special needs or multiple disabilities and responsive to the needs of recipients both of General Assistance and Temporary Assistance to Needy Families **(R20)**.

The creation of jobs consistent with the health limitations of many people with HIV/AIDS is one challenge that the City must meet in order to realize the benefits of moving previously disabled San Franciscans into productive employment. According to several surveys, the majority of disabled people with HIV/AIDS considering employment wish to work 21-30 hours per week (see *Seattle 1997, Atlanta 1997*). Jobs in this category often do not include access to health insurance, which provides the majority of savings in moving people from disability into employment (see *Kemp and Kahn 1998*). Accordingly, the Subcommittee recommends a series of measures to foster job identification and creation: the inclusion of people with HIV/AIDS who are economically disadvantaged as a target for first-source hiring in the pending emendation of the San Francisco Administrative Code, including special consideration for people with symptomatic or disabling HIV/AIDS whose asset base has been depleted as a result of their disability; leadership by the City in identifying appropriate transitional work opportunities within its workforce; promotion of the employment of people with HIV/AIDS under publicly-funded AIDS service contracts, as eloquently advocated by *Perkins 1997*; an initiative in partnership with the private sector, comparable to the $3.7 million San Francisco Works program, to encourage the creation of part-time jobs with access to health insurance for people with HIV/AIDS; and the development of a collaboration between San Francisco Renaissance's microenterprise program and the new HIV/AIDS Employment Development Unit **(R25-R29)**. Finally, to increase employment opportunities for people with HIV/AIDS, the Subcommittee also recommends a pilot program to subsidize health insurance premiums for 200 low-income HIV-positive residents of San Francisco who are unemployed or under-employed, do not have health insurance and are receiving health care services from San Francisco County **(R30)**. The Subcommittee also recommends that the City establish preferential treatment with businesses that provide their employees with comprehensive health insurance coverage through affirmative scoring of such coverage in competitive bidding processes **(R31)**.

The recent advances in AIDS therapies have created an opportunity for the City to assist thousands of previously disabled San Franciscans in resuming independent, productive lives within our community, while helping to alleviate the great strain the AIDS epidemic has place on our public health

and social service systems. The creation of services to assist people with HIV/AIDS in securing and maintaining successful employment will improve their quality of life, reduce costs to the taxpayer, and benefit the economy by restoring to it their wealth of talent, experience and skills.

– Report prepared by Paul A. Vander Waerdt, Ph.D.

Recommendations

Policy and Management

1. *That the Mayor designate a Department Head-level employee responsible for the coordination and monitoring of workplace entry and re-entry services for people with HIV/AIDS.*

2. *That the Mayor establish an HIV/AIDS Employment Development Committee of the Health Commission, its membership to be appointed by the Mayor, to provide planning, evaluation and policy oversight of the City's workplace entry and re-entry services, including implementation of recommendations in this Report approved by the Mayor and coordination of the efforts of City agencies. That this committee have the budgetary authority to set priorities within the various funding streams assigned by the Mayor to support HIV/AIDS employment services and that it be staffed by the Department Head designated per* ***Recommendation 1.***

3. *That the Mayor appoint the Department Head designated per* ***Recommendation 1,*** *or the Director of the employment program established per* ***Recommendation 10,*** *to the Workforce Development Steering Committee, to represent the interests of people with HIV/AIDS in City-wide employment development planning.*

4. *That the Mayor appoint a member of the committee established per* ***Recommendation 2*** *to the Private Industry Council, to represent the interests of people with HIV/AIDS in the planning, design and evaluation of job training programs.*

5. *That the Mayor appoint a member of this committee to the Mayor's Office of Community Development (MOCD) Citizens' Committee on Community Development, to represent the interests of people with HIV/AIDS in the allocation of community development block grant funding.*

6. *That the Mayor appoint a member of this committee to the Mayor's HIV Health Services Planning Council, to represent the employment interests of people with HIV/AIDS in the Council's annual assessments of consumer need and prioritization of Ryan White CARE funding, pursuant to the process for Planning Council appointments set out in the revised CARE legislation (P.L. 104-146) and the Council's established nomination process.*

7. *That the Mayor direct the Planning Council to seek clarification from the Health Resources and Services Administration of the U.S. Department of Health and Human Services (HRSA) concerning the eligibility for funding under the Ryan White CARE Act of case coordination and information and referral services that link consumers of the CARE-funded AIDS service delivery system with the resources of the state Department of Rehabilitation, pursuant to Director Anita Eichler's July 1, 1997 clarification of Program Policy Notice 97-02 (see* ***section*** *4). If HRSA's policy clarification is affirmative, that the Planning Council consider funding such services in order to increase the overall resources available for people with HIV/AIDS in San Francisco and to facilitate the redirection of CARE funds to the most severely disabled.*

8. *That the Mayor direct the Planning Council to review the CARE legislation (P.L. 101-381,104-146), existing Planning Council policies and the Department of Public Health's contract language in order to develop and adopt consistent policies and procedures, to be enforced through the Department's Office of Contracts Management and Compliance, with respect to continued utilization of CARE-funded services by consumers who have entered or re-entered the workplace. That these policies provide for continued access to CARE-funded services for a transitional period for HIV-positive employees without health insurance, whose income from employment might nominally render them ineligible for these services, and for a transitional period for insured employees not shorter in duration than any pre-existing exclusion clause in their insurance.*

9. *That the City direct its Washington, D.C., lobbyist to support recommendations for the reform of Social Security trial work programs developed by the National Council on Disability.*

Service Delivery System Development

10. *That the City establish and fund an HIV/AIDS Employment Development Unit in the Department of Public Health to provide direct core services,*

including assessment, limited benefits counseling, job counseling, retention and placement services, to oversee the provision of existing HIV/AIDS employment services provided by nonprofit contractors, and to coordinate access to related services (e.g., financial assistance, client and legal advocacy, and psychosocial services) through referral to City contractors; to coordinate job training and placement through San Francisco's Workforce Development System, outstationing staff at the City's "one-stop" Career Centers in development; to link consumers of CARE-funded AIDS social services with the resources available through the State of California vocational rehabilitation system; and to plan, monitor, track and evaluate the quality of employment services for people with HIV/AIDS on a system-wide basis, including consumers served by the Department of Human Services, the Private Industry Council, the San Francisco Human Rights Commission and other City departments, agencies, affiliated entities and nonprofit contractors.

11. *That this Unit provide technical assistance to appropriate nonprofit contractors to assist them in working effectively together to deliver HIV/AIDS employment services and to integrate available resources into a comprehensive, coordinated and cost-effective employment service delivery system.*

12. *That this Unit collaborate with the California Department of Rehabilitation, Private Industry Council, Department of Human Services, San Francisco Human Rights Commission and community-based organizations to develop a training program designed to increase the effectiveness of AIDS service organization case managers in meeting the employment service needs of people living with HIV/AIIDS and of vocational counseling and training staff in responding to the unique employment-related needs of people with HIV/AIDS. That completion of this training be mandatory for all City-funded AIDS case management personnel and employment specialists at the Department of Human Services, and that it be made available to appropriate personnel in other City agencies and contractors.*

13. *That the Department of Public Health revise its standards of AIDS case management practice to include vocational rehabilitation as a required competence for all publicly-funded AIDS case management and client advocacy positions. This competence may be established through certification as a rehabilitation counselor, possession of another professional qualification in vocational rehabilitation accepted by the Department Head designated per* ***Recommendation 1,*** *or successful completion of the training program established per* ***Recommendation 12.*** *That the Department of Public Health consult with the San Francisco*

Human Rights Commission, the Department of Human Services and the California Department of Rehabilitation in revising its standards of AIDS case management practice pursuant to this recommendation.

14. That the HIV/AIDS Employment Development Unit coordinate linkage of the continuum of workplace entry and re-entry services to housing and housing support services by providing information and referral to employment services at intake and assessment for housing services and by making employment assessment and counseling available on a periodic basis at housing sites for people with HIV/AIDS.

15. That the Department of Public Health, Redevelopment Agency and Mayor's Office of Homelessness review all City-funded housing services for the homeless and people with HIV/AIDS, particularly the policies and procedures of homeless shelters, to ensure that they accommodate consumers' reasonable work schedules and promote employment wherever possible. That the Department of Public Health review the scheduled hours of city clinics and AIDS service organizations to ensure that people with HIV/AIDS who are working have reasonable access to services.

16. That the City provide HIV-positive consumers who are homeless or at risk of homelessness with access to voice mail, job search skills development, and other appropriate assistance including clothing vouchers, to increase their capacity to complete their individualized employment service plan. This service could be provided by entering into a contract with an appropriate community-based organization, through the Access Point Centers recommended by the Adherence Subcommittee, or through ensuring that homeless agencies already funded by the City to provide such services are responsive to the needs of HIV-positive consumers and effectively linked with the AIDS service delivery system.

17. That the Department of Public Health establish psychosocial services tailored to the employment needs of people with HIV/AIDS, including those seeking to retain their employment, through review and modification of existing CARE and General Fund contracts. That these services be coordinated with workplace entry and re-entry services at the point of initial intake and assessment.

18. That the Mayor require all City departments, agencies and affiliated entities that provide or fund direct services to develop mechanisms to identify and track self-identified HIV-positive consumers, conduct a formal assessment of their social service and employment needs, and prepare a specific Action Plan for the Mayor's review and approval to assure provision of service in proportion to the overall population eligible

for these services. That the Mayor prioritize Department of Human Services, the Mayor's Office of Community Development, Private Industry Council, the San Francisco Redevelopment Agency and the San Francisco Housing Agency in the preparation of these Action Plans. That the City give consideration to implementing a system that utilizes an anonymous coded identifier to track HIV-positive consumers and their service needs.

19. *That the Department of Public Health work in concert with the Department of Human Services to identify the social service needs of the latter's HIV-positive consumers in the General Assistance and Temporary Assistance to Needy Families programs, to develop system linkages to ensure these consumers' access to existing CARE-funded services, and to assist the Department of Human Services in the planning and implementation of such additional services as are needed by the Department of Human Services' HIV-positive consumers.*

20. *That the Department of Human Services establish an HIV unit accountable -- in coordination with the HIV/AIDS Employment Unit of the Department of Public Health -- for the identification, tracking, delivery and evaluation of services for people with HIV/AIDS, including those with special needs or multiple disabilities and responsive to the needs of recipients both of General Assistance and Temporary Assistance to Needy Families.*

21. *That the Department of Human Services notify all consumers at intake of the availability of AIDS-specific social and employment services, and that it create incentives for consumers to self-disclose their HIV status, thereby promoting early intervention and identification of medical and social service needs. These incentives may include access to CARE-funded services, including emergency vouchers, child care and other services.*

22. *That the Mayor prioritize funding to enable the San Francisco Human Rights Commission to maintain and expand its HIV/AIDS in the Workplace technical assistance project through development and updating of its training materials, continued provision of mediation in cases where discrimination in employment, housing, or public accommodation is alleged on the basis of HIV status, an expanded program of outreach (including workshops and technical assistance) with emphasis on small business and on for-profit temporary placement agencies, and creation of a mandatory training program to educate all City managers about their responsibilities under the Americans with Disabilities Act. That in developing its outreach program the Human Rights Commission consult with other providers of technical services to employers (e.g., Pacific Disability Business and Technical Assistance Center, Jobs*

Accommodations Network, Equal Employment Opportunity Commission HIV/AIDS Division, and Life Employment Program of IAM CARES) to minimize duplication and promote effective coordination of available resources.

23. That the Private Industry Council fund 1998 information and referral as well as job training services for people with FHV/AIDS to facilitate their access to training programs, at a level to be determined by review of their job training needs (see ***Recommendation 18****).*

24. That the San Francisco Redevelopment Agency enter into a contract with an appropriate provider to provide jobs and job training for people with HIV/AIDS in conjunction with its community and economic development services, consistent with existing contracts with nonprofit agencies serving other communities.

Job Identification and Creation

25. That people with HIV/AIDS who are economically disadvantaged be considered as a target for first source hiring in the pending emendation of the San Francisco Administrative Code to establish specific requirements and procedures for hiring of qualified economically disadvantaged individuals through provisions included in City contracts and in permits for development projects. That people with symptomatic or disabling HIV/AIDS whose asset base has been depleted as a result of their disability receive special consideration for classification as "economically disadvantaged".

26. That the Mayor direct all City departments, agencies and affiliated entities to identify appropriate transitional work opportunities for people with HIV/AIDS seeking to enter or re-enter the workforce, the listing of which shall be administered by the HIV/AIDS Employment Development Unit.

27. That the Director of Public Health prepare a report for the Health Commission on the recruitment, hiring and retention of self-disclosed HIV-positive employees in publicly funded AIDS service organizations, that this report identify the number of such employees hired under each CARE or General Fund contract, identify common barriers faced by people with HIV/AIDS to employment in AIDS service organizations and that it propose model hiring policies and practices to promote the employment of people with HIV/AIDS under publicly funded AIDS services contracts.

28. That the City establish a partnership with the business community, comparable to the San Francisco Works program, to provide suitable jobs for people with HIV/AIDS who seek to enter or re-enter the workforce. That the City prioritize creation of part-time jobs with access to health insurance in its partnership with the private sector.

29. That the City fund San Francisco Renaissance to provide microenterprise development services for people with HIV/AIDS, in collaboration with the HIV/AIDS Employment Development Unit.

30. That the City fund a pilot program to increase employment opportunities for people with HIV/AIDS by subsidizing health insurance premiums for 200 low income HIV-positive residents of San Francisco who are unemployed or under-employed, do not have health insurance and are receiving health care services from San Francisco County. That this program subsidize premiums of up to twelve months for each eligible person -- a 100% subsidy for the first six months, and 50% subsidy for the last six months -- who is hired by a nonprofit organization of any size or by any for-profit business located in San Francisco with 50 or fewer employees that meets certain minimum standards for their group health insurance coverage (e.g., benefits, limits on deductibles).

31. That the City establish preferential treatment with businesses that provide their employees with comprehensive health insurance coverage through affirmative scoring of such coverage in competitive bidding processes. That the City conduct a study to determine the appropriate weight of the scoring based upon cost avoidance to relevant City Departments and agencies.

Legislation

32. That the City support state and national initiatives to remediate the disincentives to workplace entry and re-entry arising from federal, state and private disability insurance policies and practices, and that it lend all possible support to ensure that the 1998 successor of Assemblywoman Migden's AB 1099 becomes law.

33. That the City work in concert with Assemblywoman Migden's Office, community-based organizations and the AIDS Budget Coalition to support a 1998 allocation from the California Legislature for four demonstration projects and statewide training and technical assistance to establish cost-effective workplace entry and re-entry programs for people with HIV/AIDS.

Evaluation and Data Collection

34. That the Department of Public Health conduct or fund (a) a consumer needs assessment (patterned, e.g., on that conducted by the Northwest AIDS Foundation); (b) an evaluation project to track utilization of social and medical services by consumers who have registered for workplace entry or re-entry services and their cost-effectiveness and their fiscal impact on the City budget; and (c) a study of the impact of the new therapies on the relationship between disease progression, development of functional limitations and employment in San Francisco's HIV-positive population.

35. That the Department of Public Health include employment in its annual survey of consumer need and satisfaction, funding it if necessary from non-CARE funds, to facilitate informed system-wide funding allocation decisions through development of comparative measures of unmet need that include employment.

Marketing

36. That the Mayor's Office implement the Subcommittee's Media Campaign Proposal in which the Mayor serves as spokesman in a Spring 1998 print, radio and television media campaign to publicize the City's new continuum of workplace entry and re-entry services for people with HIV/AIDS. An agreement has been secured from Saatchi and Saatchi to provide creative direction for this campaign on a pro bono basis.

37. That the City create and maintain a website to promote its initiative to create employment services for people with HIV/AIDS. An agreement has been reached with IDEAS: for advertising and design in San Francisco to provide creative direction on a pro bono basis. That the City give consideration to creating this website as part of the on-line directory of employment services currently in preparation by the Private Industry Council with funding from the U.S. Department of Labor.

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Housing

The issues of housing for people living with AIDS in the age of protease inhibitors and three-drug combinations are enormously complex. Prior to these medical advancements, housing was already beginning to be a serious issue due to the expense of medicines, cost of care, rising rents and lack of availability of affordable housing. And although these are problems that all San Franciscans share, living with the HIV virus exacerbates an already difficult situation.

People with AIDS and HIV are living considerably longer (although that trend had begun prior to the introduction of protease inhibitors) and obviously their housing needs have drastically changed. New strategies are needed for dealing with a growing population of people who are healthier but perhaps not ready for full employment, people who in order to survive need to be able to focus more on health issues than shelter or food. Availability and adherence to the new drug combinations will mean the difference between life and death for the HIV infected population. Adequate, stable housing is a necessary component to achieve those goals.

Background

In 1990, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) to provide emergency resources for services in localities which have been disproportionately impacted by HIV (Title I), health care support services (Title II) and early intervention services (Tittle III). CARE funds are administered by the Health Resources and Services Administration of the United States Public Health Service. Locally the San Francisco Department of Public Health AIDS Office administers the funds. Priorities are set by the Mayors' HIV Health Services Planning Council.

In 1990, federal legislation created the Housing Opportunities for Persons with AIDS (HOPWA) program under the Department of Housing and Urban Development (HUD). The Federal legislation provided for a long list of eligible activities including: housing information services counseling, resource identification, long term rental assistance, supportive services, and building or remodeling of AIDS facilities. It is locally administered by the San Francisco Redevelopment Agency.

HOPWA and CARE funds arrived in the metropolitan area consisting of San Francisco, San Mateo and Marin in 1992. The 5-year HIV Housing Plan was developed to guide housing development for persons disabled with HIV and AIDS. This plan dealt with the competing priorities among the eligible activities and focused San Francisco's HOPWA assistance in the following areas: Rental Assistance, Capital, Supportive Services, and Technical Assistance. The plan also included the allocation of rental assistance and capital for new AIDS-related housing. Rental assistance was seen as a means of providing immediate assistance to those in need of shelter and financial assistance to those burdened by rent payments. Capital expenditures were seen as long term investments in creating housing that would be permanently available specifically for person with HIV/AIDS and not dependent on ongoing subsidies. The agreement resulted in 65% of the funds directed for capital, 15% for services, and 20% for rental assistance. Among the capital needs identified were hospices and other licensed facilities. Though HOPWA had great flexibility in its use, the program was seen as a producer of housing with funds from CARE to be used to operate these facilities after an initial period.

After capital funds were distributed, 16 developments containing over 240 units were developed. Of these units, 113 beds were in licensed facilities. The HOPWA funds assisted in the construction and rehabilitation of all the licensed facilities for persons with HIV/AIDS in San Francisco outside of institutional settings. The balance of units assisted by HOPWA funds was independent housing. The non-licensed developments served a variety of populations including persons with substance abuse and psychiatric problems, women and children, families, and single individuals. In the past year, the Agency has worked to incorporate HOPWA units within larger affordable housing developments assisted by the Agency and the Mayor's Office of Housing. An achievement of the program was to provide housing targeted to persons with AIDS and permanent locations to groups such as the Black Coalition on AIDS and Maitri, which continue to this day.

To assist potential clients identify available housing assistance, the Centralized Housing Information and Placement Service (CHIPS) was created.. CHIPS applicants have provided preliminary information on their income and type of housing assistance requested. A total of 5,437 persons have registered with CHIPS for HIV/AIDS housing assistance. It is from this list that applicants are referred to permanent housing and to rental assistance providers. A total of 1,884 persons have been placed in housing for some period of time. Emergency housing and hospice providers are not required to use CHIPS. The goal of CHIPS was to provide a central place for those desiring housing assistance rather than the prior process of each housing facility maintaining a separate list.

Among the problems experienced with CHIPS was that the initial implementation was slow. There were also problems related to how quickly names were taken from the list and provided to the housing provider. Lastly, the demand for housing assistance continues to exceed the supply. One of the areas to be evaluated is how to prioritize those on CHIPS to ensure quicker service to the neediest.

The rental assistance program was modeled after the Housing Authority Section 8 leased housing program and is administered jointly by the Housing Authority and Catholic Charities. The rental program has been successful in leasing over 300 units but its experience sheds some light on the challenges faced in serving very low-income persons with HIV and AIDS. Clients who successfully complete the applications have 120 days to find an apartment that meets the Housing Authority Housing Quality Standards and has a rent less than the "Fair Market Rent." The Fair Market Rent is the rent at the 40th Percentile for recent movers. In other words, 40% of all those who moved within the last 12 months paid less than this standard.

Catholic Charities and the Housing Authority are attempting to increase the number of households assisted. Recently, Catholic Charities requested additional 150 households from the CHIPS list. Based upon Catholic Charities', prior experience approximately 20% of these households will find apartments. Looking behind these numbers it appears that of those on the list only 60% of those referred from the CHIPS list will actually complete the needed applications. Of those that complete applications, approximately 36% will find apartments. Those that do not complete applications include those that can not be located and those that choose not to participate in the program. For those that do choose to participate, they are competing in a rental market with less than one- percent vacancy. The rents subsidized under the program must be below the FMR. Among recent applicants whose certificates expired after the 120-day period, 9 of 23 cited the fair market rent as an obstacle. An equal number had mental, physical, and substance abuse issues.

The rental assistance program does not utilize Single Room Occupancy units since they do not meet HUD's housing standards. They do not have kitchens or complete bathrooms. A more recent occurrence has been the expiration of leases for those that were successful in finding units. As the vacancy rate has dropped, rents have risen. The landlord that had been receiving a fair rate of return with a rental certificate now sees an opportunity to increase rents at the end of the initial lease period and allows the contract with the Housing Authority to expire.

Supportive services related to housing were funded initially through the HOPWA program. After one year of operation the services were to be

funded by the CARE funds. At the time of the initial 5-year plan, both CARE and HOPWA funds were growing. As federal funding has leveled off and at a time when additional communities are eligible under both HOPWA and CARE programs, the local funds for under these two programs has diminished. As a result there has been a restructuring of the funding for services attached to housing.

The San Francisco Redevelopment Agency, Department of Public Health and HIV Health Service Council have recommended that the Redevelopment Agency continue to fund the ongoing service costs of the licensed facilities. Services at the permanent facilities would be funded through CARE. This agreement will create additional flexibility within the CARE budget to meet existing services and programmatic needs. This grouping of facilities results in a single public funding source for each housing development, therefore reducing duplication of contracts and oversight. For the HOPWA program the addition of the service costs will increase the program's annual financial obligations and reduce the capital available for future developments.

Housing and Medical Advances

During the fourth year of the HOPWA program operation, the general media began publishing articles about medical breakthroughs in the treatment of persons living with HIV and AIDS, specifically protease inhibitors. For many individuals, protease inhibitors greatly improved their health and prolonged their lives. For many individuals, the medical treatments resulted in temporary remission of the disease. This breakthrough occurred as developments of licensed facilities were nearing completion.

What implications did these medical advances have for the existing HOPWA /CARE developments and future HOPWA/CARE housing activities? There were questions raised about the ongoing need for licensed facilities. The current licensed residences, Leland House, Richard Cohen, and Peter Claver have been fully occupied. Maitri and Larkin Street residences opened their doors in December of 1997. Larkin Street serves youth, 18 - 23, which is a population that has not been accessing health services. Within three months, both Larkin Street and Maitri will be fully occupied.

The future need for licensed facilities will be dependent on the success of the current treatments and the development of new medical treatments. But these treatments are expensive and require a rigid adherence to a medication schedule. There will be those individuals who, for whatever

reason, are unable to afford or to adhere to such a schedule. There will also be those individuals whose HIV status is but one of multiple personal challenges. The licensed facilities are coordinating their outreach efforts. Each of these facilities is attempting to create a niche to provide services to those in need but not duplicating or competing with other facilities. Some of the licensed facilities also have the ability to evolve to a less medically oriented living environment while continuing to provide service enriched housing to persons with HIV/AIDS.

Even for those whose treatment is successful in keeping the disease at bay, the question of housing needs remain. For each individual, it will be a question of financial resources. Will individuals be well enough to work? Will their disability payments continue? To attempt to answer some of the above questions, the Redevelopment Agency submitted a grant proposal to HUD, developed after consultation with community leaders and consumers.

The proposal would have created a shallow rent subsidy program to provide financial stability to individuals considering returning to work. The rent subsidy program was designed to test some of the perceived impediments to additional use of rental subsidies under the existing program. The program would allow units with rents in excess of 120% of "fair market rent", single room occupancies, roommate situations, and households paying in excess of 30% of income for housing. This housing assistance would be only for the term of the individuals' participation in occupational and vocational training to assist in resolving issues related to workplace re-entry, including potential loss of existing financial assistance. Unfortunately, the grant application was denied. But based upon the support for the original proposal, it is the intent of the Redevelopment Agency to implement a program with existing HOPWA funds.

For those individuals that are not as healthy and who have other problems, housing remains the foundation on which to build healthier lives. Medicine taken underneath a freeway does not have the effectiveness as that which is taken in an apartment.

Homelessness

Insufficient income, unemployment, lack of affordable housing, the de-institutionalization of the mentally ill, and cutbacks in social support services contribute to the increasing numbers of homeless in the San

Francisco area. According to the mayor's Office of Homelessness, San Francisco has the second highest per capita rate of homelessness in the United States with approximately 16,000homeless people (including an estimated 2,000 homeless and runaway youth).

An estimated 30 to 40% of the homeless population have mental health problems, while 30 to 60% have substance abuse problems *(Fischer, 1991)*. The level of TB infection for this population is 33% -- ten times the rate of San Francisco as a whole and 40 times the US rate. It is estimated that 9% of homeless people are infected with HIV *(Bangsberg et al 1997)*. A survey of homeless gay/bisexual men at shelters and food lines found that 40% were HIV-infected *(Zolopa, 1994)*. Among homeless gay/bisexual male youth (=<24 years), 45.1% were infected with HIV *(Department of Public Health, 1996)*. It is estimated that 27% of homeless HIV-infected individuals in the EMA are without access to either new drug therapies or the primary care necessary to begin treatment *(Bangsberg, 1997)*.

While levels of drug and alcohol abuse, and mental illness are high for the entire homeless population, those homeless individuals without a primary care provider are more likely to report concomitant substance abuse and severe mental illness, and more likely to report frequent use of the emergency room. For this sub-population, multiple-diagnosis represents a barrier to integration into care and severely limits their options for treatment. Bangsberg's research indicates that adherence to the tough drug protocols is not the major issue. In fact homeless people have acceptable adherence rates. The issue seems to be access. The less stable the housing situation, the less likely a person is able to access the needed drugs.

Planning

As a result of the changes in the funding, the epidemic, and an apparent shift in the need for housing, the Redevelopment Agency has contracted with the Corporation for Supportive Housing to update the Five-Year HIV Housing Plan. The Update will attempt to address questions related to the type of future housing to be developed and services to be provided. The Update is also intended to assist the Agency in evaluating improvements to the existing service system and whether all segments of the eligible population are being served. The Update will guide the Redevelopment Agency and the CARE Council in future HOPWA and CARE funding decisions.

For those receiving housing assistance of some sort, it is anticipated that the housing assistance will be needed for a longer time. It is also

anticipated that there will be no further growth in the number of individuals requiring licensed facilities. For those not currently being assisted by the HOPWA/CARE programs, what type of future assistance is most appropriate? How will individuals who are poorly housed find units at a time when rental vacancies are less than one percent? If they find a vacant unit will they able to afford it?

Early results of the Update indicate there remains a need to provide supportive independent housing. Many of those not being served by the rental assistance program either are not succeeding in leasing a unit or are being evicted and require supportive services. The delivery of those services independently is less efficient than in a supportive housing environment. The model often mentioned is an independent unit such as a Single Room Occupancy room (also referred to as residential hotel room) or studio apartment within a larger building with community facilities to provide a range of services from substance abuse to mental health counseling.

The study also points to a need to improve access to the rental assistance program. Improving the rental assistance program may be more daunting than the construction or rehabilitation of new housing. The San Francisco rental market and the nature of federal rental assistance programs compound the challenges faced by the rental assistance program.

Extremely low income and homeless populations with and without AIDS are served by a variety of City programs beyond HOPWA. An ongoing challenge is the coordination of programs funded under HUD's McKinney Homeless Program, as administered by Health and Human Services, to ensure that formerly homeless residents receive specific HIV/AIDS services. The goals of the HOPWA housing program and other City programs are summarized and coordinated in the City's Consolidated Plan.

The HOPWA program is but one part of the service delivery system for persons with AIDS. The program has experienced success in the delivery of services to date but challenges remain in rental assistance, service, and capital development programs. As HOPWA proceeds, its activities must be coordinated with consumer groups and community based housing and service providers. Its activities must also be coordinated among City departments including the Department of Public Health, the Department of Human Services; the Mayor's Office of Housing and the Redevelopment Agency. It should also be noted that as a good beginning of collaboration, Supervisor Amos Brown recently passed legislation initially intended to fund from the City's General Fund assist PLWH/A re-entering society from institution release. Although there was an unfortunate delay due territorial battles, $200,000 was made available for rental subsidies. It is hoped that in the future more funds will be made available for these special needs.

Recommendations

These recommendations are based partially on draft recommendations from the Update. AIDS Housing of Washington held four public forums including both providers and service recipients. Included are recommendations from the CARE council's housing committee, which held numerous public hearings during the year. The San Francisco AIDS Foundation also submitted some recommendations.

Recommendations:

HIV Housing Summit

1. *Set a date for an HIV housing conference as soon as possible. Housing issues in general are complex. Adding HIV into the mixture creates a need for a high level of discussion. Bring together the city policy heads in charge of AIDS, Housing, and Homeless along with AIDS advocates and outside experts in housing and AIDS fields. The HIV housing "model" was brought into existence at a time of crisis and is an emergency model. Although the housing crisis is still with us, we have to acknowledge that HIV and all the inherent housing problems will be with us for a long time to come. We must create a working model that works in collaboration with all the relevant city departments.*

Working Committee on HIV Housing Policy

1. *In advance of the Housing summit and continuing until there is no longer a housing crisis, there should be a committee meeting on a regular basis to set City HIV housing policy. The committee should be comprised of the department heads of the Mayors Office of Housing, Homeless, Community Development, the Redevelopment Agency, the AIDS Office, and a representative from the CARE Council and other appropriate experts. The financing of housing for people living with AIDS and HIV is complex and multi-departmental. HOPWA and CARE funds have greatly assisted the operations of all the above agencies by aiding people who might have otherwise required funds from those agencies and departments. In a collaborative effort there should be a thorough examination of the funding streams and a collaborative effort to solve the housing crisis.*

Rental Assistance

1. *Convene a working group to consider eligibility criteria, consolidation of administrative functions and to explore consistency with other rental assistance programs in the city including Shelter Plus Care and those programs targeting homeless persons.*

2. *Analyze work with the Comprehensive Housing Affordability Strategy Committee to develop a search and referral program to assist AIDS housing clients to find appropriate affordable housing.*

3. *The Redevelopment Agency must work with local agencies and HUD to adjust Fair Market Rents to reflect market conditions and to eliminate the "economic" eviction loophole.*

Needs Assessment

1. *A study should be immediately undertaken to accurately assess the actual number and level of housing needs of people living with HIV and AIDS. The current knowledge is from a patchwork of different studies many outdated or not complete. An in depth study would greatly facilitate the planning of housing policy.*

Capital Projects

1. *Seek additional opportunities to use HOPWA funds as a leverage for set-asides in mainstream affordable housing projects for single adults and families, with the priority on funding projects that include at minimum a studio with kitchen and bath.*

2. *Convene a working group to define harm reduction for housing programs for people living with HIV and AIDS.*

3. *Establish a size-based housing program based on a harm reduction model for people living with HIV and AIDS with substance abuse and/or mental illness.*

4. *Explore incorporating this program into a larger housing development for low income and/or homeless people in San Francisco.*

5. *San Francisco must create additional housing, including the renovation and rehabilitation of existing building and make efficient use of existing housing stock, such as that on Treasure Island and in the Presidio.*

6. *San Francisco's political leaders must also protect the right to privacy of HIV housing and oppose any posting measures.*

Licensed Projects

1. *Develop centralized outreach program to work with mental health providers, hospital discharge planners, etc. to facilitate enrollment of individuals on the CHIPS list and placement of individuals into appropriate Residential Care Facilities for the Chronically Ill programs, and to explore linkages to existing emergency and transitional programs.*

2. *Clarify what types of health and social service needs specific RCF-CL programs can address in their programs and evaluate staffing and core competencies of each program to determine if RCF-CL programs should explicitly target certain sub-populations.*

CHIPS

1. *It is widely acknowledged that the CHIPS list is not an accurate reflection of the current housing need. There are many people who are unaware of the existence of the list. The list also does not take into account the actual level of need. It is basically a first-come first-served list. The CARE Council has moved into prioritizing on a need basis (e.g., health status, homelessness or border-line homeless). The CHIPS list should be similarly prioritized. The list should be able to account for need or a separate delivery system devised to prevent homelessness, provide housing or vouchers to homeless, or take into account acute medical needs. There are people on the waiting list that could become homeless for want of a small shallow rent subsidy.*

2. *Develop user friendly educational materials and training for consumers as well as providers on the CHIPS program including enrollment, waiting list, and housing programs that utilize the CHIPS list and program specific eligibility criteria.*

3. *Develop a mechanism to facilitate movement of clients transferring from residential care facilities to other less costly housing when their care needs change.*

4. *Streamline intake process of CHIPS and AIDS housing programs to minimize duplication.*

Homelessness Prevention

1. *Develop guidelines and implementation strategies for a pilot shallow rent subsidy program intended to prevent evictions that include an evaluation component. Guidelines should include caps on income and rent levels.*

2. *Establish a homelessness prevention program for individuals who face eviction that offers immediate access to services and financial assistance. Include an evaluation component.*

3. *The City must advocate the protection or increase of housing resources at the federal, state and local levels, including HOPWA, Section 8 and McKinney.*

Homeless

1. *Assess existing capital programs and rental subsidy programs for people living with HIV/AIDS to identify those that can make changes in admission policies or service program that would improve their levels of service to homeless people. Provide technical assistance and/or training to improve the ability of these programs to serve homeless people.*

2. *Convene a working group, that includes homeless service providers, CHIPS administrators, and case managers, to identify and implement strategies to maintain contact with and/or track homeless and at risk individuals on the CHIPS list to ensure that as many as possible remain engaged with the system through comprehensive intake and placement.*

Systems Integration

1. *Develop cross representation between the CARE Council and the City's CHAS, McKinney application Review Panel, Shelter Plus Care program, and Long-term Care Task Force.*

2. *Develop an on-going mechanism of continuing education for CARE Council regarding AIDS housing issues, homeless programs and integrated services programs.*

3. *The City should assist housing providers in developing programs that integrate various populations, services, and funding sources, and provide new housing models.*

4. *The City should assist housing providers in identifying and applying for non-HIV specific housing funds such as McKinney or Community Development block Grants.*

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Other Issues
Subcommittee Report

The purpose of this subcommittee is to address some of the issues which, due to time constraints, could not be considered at length at the Summit. This section contains additional concerns that we felt needed to be out on the policy agenda for consideration. It is not intended to be an exhaustive listing of all other AIDS problems, but rather to provide the stimulus for discussion of other factors that will affect the course of the epidemic in the future.

Accountability of AIDS Service Organizations

The systems and institutions for AIDS care and HIV prevention that have grown up in this epidemic are perhaps the greatest illustration of a community's response to a public health disaster that the world has ever seen. Early grass roots efforts have made a difference in the ways we understand the disease, prevented its spread and progression, educated the community about the realities of treatment and transmission, and provided needed services that weren't readily available from corporate and government entities. While we have not created the perfect system in San Francisco, we have created something of a marvel given the nation's more general failings in healthcare delivery and the population's slow acceptance of people struggling to survive AIDS.

However, over time this outstanding model of service and care delivery has become the AIDS industry – a big business and a means for furthering profitable careers. The phenomena of professionalism, centralization and routinization without important input from people living with HIV have crept into the dynamic of some AIDS service organizations. Although a part of this professionalism has had a hand in shaping how we have responded to the many complexities of the epidemic, it has also shed light on what constitutes community power and participation.

From the beginning, participation from people with HIV has been a valued aspect in legitimate AIDS work, but some AIDS service organizations have lost sight of what that means. For example, some organizations allow community members and clients to make public comment in their meetings, while at the same time seem unwilling to work with other people outside their organization. Some AIDS service organization board meetings are open to the public. Yet their structures prevent many community members from

serving on them and from giving input to the most crucial issues. Even if community members are allowed to participate in the process they may never see their advice implemented for trivial political reasons.

Lately in the City, there have been a number of complaints and accusations from all sides. Unfortunately, personalities sometimes sidetrack the real issues at hand. But equally unfortunate is institutional response, which characterizes the so-called "few dissenting voices" as excessive, with patronizing rhetoric that suggest the organization's policies should not be questioned. Many AIDS service organizations seem to have become omnipotent and therefore unaccountable.

No one group is responsible for all of the accountability problems. Much good work is being done by our AIDS service organizations, but we must also recognize that different organizations have different standards of accountability or aren't accountable at all. Service providers must not become like the government institutions and pharmaceutical industry we fought so hard to change early in the epidemic. If we are truly going to accomplish the service improvements needed in the coming years, we must include people with AIDS in every level of decision making.

Recommendations:

1. *All organizations that serve people with HIV and AIDS in San Francisco and elsewhere must be called onto examine ways to invite and encourage participation from the affected community. Pending legislation in the Board of Supervisors to require city-funded non-profits to adhere to the Sunshine Laws is one positive approach. Further accountability provisions should be mandated from the HIV Prevention Planning Council and Ryan White Health Services Planning Council. Most importantly, AIDS service organizations should just do what is ethical and LISTEN to people directly affected by this disease.*

Emerging Epidemics

As dramatic improvements are being made in HIV treatment and prevention, disturbing new epidemics loom on the horizon, threatening to reverse our progress.

The prevalence of Hepatitis C in people with HIV is a growing concern. There are no effective treatments for Hepatitis C and the disease can be life-threatening, especially with co-infection with HIV. Hepatitis C is especially

common in IV drug users. The problem is compounded by the liver damage caused by many drugs for HIV and opportunistic infections.

Although the rate of tuberculosis is down in San Francisco, infection control and treatment must continue to be a priority due to the seriousness of co-infection with HIV and the highly infectious nature of TB. TB disproportionately affects immigrant and minority populations. TB rates rose in the late 1980's, due to cuts in funding and increasing HIV co-infection.

As people with AIDS return to relative health, there is increasing concern that many are returning to use of recreational drugs, which can cause potentially serious interactions with HIV medications, further damage to the immune system, and behavior that puts themselves and others at risk for infection.

Recommendations:

1. *The Health Department must remain vigilant about emerging epidemics, to which people with HIV are particularly vulnerable. Greater public information efforts should be undertaken to educate the community about risks and prevention.*

2. *Funding must be maintained and increased, if necessary, to treat multi-drug resistant strains of TB and to develop better methods for control and prevention.*

3. *More effective prevention efforts need to be undertaken to educate HIV-positive people about the dangers of recreational drug use and other substance abuse.*

Needed Research

As new combination therapies improve the health of people with HIV disease and ultimately delay HIV progression, more research should be focused on repairing broken immune systems. While much understanding of the immune system has long been accomplished because of HIV, there are still gaps in understanding how the body is affected by long-term HIV disease. How effective is highly active antiretroviral therapy on immune function? How can immune-based therapies be made available and affordable to all who need them? Further research into cytokine and chemokine function, gene therapy and immunosuppressive techniques are

hopeful therapeutic possibilities that the Bay Area has tremendous resources to research.

HIV mutation as a result of the misunderstanding of drug delivery is currently a major issue in stopping the disease. Mutations need to be sorted out and diagnosed efficiently so that appropriate interventions can be made. Cross resistance of HIV therapies needs to be proven in clinical research and effective treatments that are not cross resistant need to be developed and researched. New generations of therapies that target other HIV reproductive enzymes are key to treating multi-drug resistant patients who have few options left.

There continues to be conflicting data regarding re-infection. Until this issue is sorted out, we may be risking the spread of highly resistant HIV strains that could be difficult, if not impossible, to treat. In the meantime, safer sex messages need to be reinforced until the possibility of re-infection is ruled out. Until we have more answers, placing blame on people with HIV only creates fear and oppression.

In 1998, we should see the beginning of a larger focus on a preventive AIDS vaccine. With the high cost of therapies, the world has woken up to the reality that a vaccine will be the only way to control the epidemic worldwide. San Francisco has a part to play because we have high enough seroincidence to be a site for vaccine trials, and because vaccines will be tested in combination with other prevention interventions. Furthermore, San Francisco may be the site for research in developing better vaccine candidates. Advocates for a vaccine believe strongly that a vaccine should become part of the AIDS agenda without taking away from treatment or other prevention efforts, since we have no way of knowing when a vaccine will be developed or how effective it will be.

Recommendation:

1. *The City is the home to one of the nation's leading AIDS research institutions, the University of California, San Francisco, as well as a wide network of clinical trials and biotech firms. We urge these institutions to explore greater research in the areas of immune function, resistance/re-infection and vaccine development.*

End of Life Care

Despite all of the new therapies and breakthroughs in the management of opportunistic infections, a person with HIV is still infected with a chronic, potentially fatal illness. The long-term efficacy of new medication regimens remains to be seen and long-term side effects have yet to be determined.

Anecdotally, of all the persons who attempt triple-combination therapy, about 25-33% are unable to tolerate them. Also, drugs may not be effective in bringing virus levels to undetectable levels in a large number of people. Without modification of the current medications or new drug development, and further research, these persons may succumb to their HIV infection.

In addition, there are populations of people with AIDS in San Francisco who, for a variety of reasons, are not accessing care for HIV or are entering the care network at end-state disease. Some persons do not seek out health care. Others are unaware they are even infected. For some, their lifestyle or living conditions are not conducive to the regimens required for successful treatment.

The upshot of all of this is: there will continue to be a significant number of people who will die of AIDS until a cure is found.

Recommendation:

1. *The City must continue to adequately fund and support primary medical and emergency care, skilled nursing services, attendant/volunteer services, psychosocial case management support, community resource support, nutrition services, palliative care and hospital services for people with HIV and AIDS.*

Action within the African-American Community

The needs of the African-American community around HIV and AIDS are complex, in part because the community itself is complex. Conceptualizing African-American populations as monolithic has often encouraged a belief that one or two concentrated programs will serve this entire population.

Funders, service organizations, community and political leaders, and researchers must re-commit to working together to develop our awareness of

the many cultures within this culture and to building more comprehensive foundations that support our services and shape the direction of funding streams.

Following from this commitment, we recommend a few key steps that should be implemented with the aim of improving and further developing HIV and AIDS related services for African-American people in San Francisco.

Recommendations:

1. *The City, with the help from leaders and members of the community, must lead HIV/AIDS, social service and health organizations in the development of a comprehensive multi-agency strategy that details the various roles local agencies will take in serving African-American people's needs around HIV. As part of this effort, the City should also assist organizations to collectively develop their strategic plans and capacities to respond to upcoming changes in various forms of funding.*

2. *Formulative research with Bay Area African-American people must be done so that we can better grasp the complexities of the community and create better health and HIV prevention programs. In addition, effective evaluation methods must be created that assist existing programs in their development and in the creation of new programs.*

3. *On-going technical assistance must be organized by the City for all agencies serving African-American people. This support should include: steady circulation of research focused on African-American populations, trainings in creating and implementing a variety of outreach programs that are culturally congruent, and agency-level workshops that focus on how HIV and AIDS and issues of class, racism and homophobia influence different aspects of the community in different ways.*

4. *The City should take a central role in facilitating a very visible leadership campaign that is aimed at encouraging and supporting community leaders in their efforts to bring a greater awareness to all aspects of the community around African-American people's health issues and specific needs around prevention.*

5. *Local funding streams must provide not only stable resources but also develop dissemination processes that are more responsive to the complex and diverse financial schedules of a range of service providers and programs. They must also provide resources for more direct and consistent media campaigns for African-American men.*

6. *The City of San Francisco, with the leadership of Mayor Brown, should co-sponsor with the Black Coalition on AIDS a regional policy conference on African-Americans and AIDS to advance the agenda for prevention and care for people with AIDS.*

Treatment Issues

Although tests that determine the genotype and phenotype of HIV have not been validated, they are used widely in research to determine HIV resistance. Bay Area physicians are prescribing the tests whenever possible to help determine a course of treatment. However, as with viral load assays, it will probably be a matter of time before the tests are an important component of treatment decisions. Currently, the tests are expensive and, because the Food and Drug Administration has not approved them, they are not reimbursable by insurance plans.

Recommendation:

1. *A system should be put in place to enable people with HIV in San Francisco to avail themselves of the most current diagnostic techniques, such as genotype and phenotype testing, in order to stay ahead of disease progression.*

Recent advances in treatment have not been entirely effective for everyone with HIV. In studies where there is a controlled population of patients, effectiveness of therapies is high. Real world scenarios, such as San Francisco General Hospital, are showing a larger number of people – up to 50% -- are "breaking through". Although their clinical health may be stable, the patients' viral levels have rebounded or have never reached undetectable levels. Pre-treated patients with detectable virus levels are having less effectiveness with the current treatments.

Providers must be educated on the most effective therapies to initiate in each particular patient population. More research must bring newer generations of therapies that do not cross react with existing treatments. Although the news is encouraging about treating HIV, people who do not respond to the treatments must not be written off. Also, the long-term effectiveness of current treatments is not known, so all patients – whether they are responding or not – should be followed closely during the course of disease.

Medical Marijuana

The AIDS epidemic furnished the first good opportunity to study marijuana in a medical condition. An application was submitted to the Food and Drug Administration to test marijuana for its ability to stimulate appetite in patients with wasting secondary to their HIV infection. Those studies were done in the late 1980's and early 1990's, showing that the drug did have benefit as an appetite stimulant. For this reason, marijuana was approved for sale in a capsule under the brand name, Marinol. Thus, the federal government has already reviewed the efficacy of marijuana in treating one condition and has, in fact, approved the drug for that indication.

A controversy has arisen as to whether smoking marijuana is superior to ingesting the drug. Many patients have reported to their physicians that smoked marijuana is, in fact, more efficacious and has fewer side effects. It was this observation which led many physicians to support Proposition 215, which made it possible for California patients to obtain marijuana for certain medical conditions.

It has long been the policy of the City and County of San Francisco to support the availability of marijuana for medical purposes for people with serious diseases.

Marijuana must continue to be available to persons living with AIDS and HIV and other diseases who wish to use it for pain management, appetite stimulation and other medicinal purposes. We deplore the efforts of state and federal officials, including the U.S. Attorney in San Francisco, to harass and close distribution centers that were established under the terms of voter-approved Proposition 215.

Recommendations:

1. *We urge the San Francisco Police Department and District Attorney to not cooperate with actions by federal and state officers to close medical marijuana centers.*

2. *We urge the Mayor, Board of Supervisors and City Attorney to provide all possible legal assistance to efforts to defend Proposition 215 in the courts.*

Federal Drug Policy

The federal government's drug policy is a total failure. The U.S. government spends more than $30 billion a year in an effort to ban the use of

mind-altering substances. Prohibition failed as a means of controlling alcohol use and it is failing as a means of controlling substance use. What works is education and treatment, not prohibition.

This ill-conceived federal program has destroyed many lives. Numerous young people are serving long prison terms for the simple crime of possessing small amounts of marijuana. Numerous individuals have been infected with HIV because the federal government, even under the Clinton Administration, will not support a needle exchange program, such as ones that have been effective in cities such as San Francisco and in several other nations. Finally, patients are deprived beneficial drugs such as marijuana because they are demonized by this federal program.

Recommendation:

1. *The Mayor and Board of Supervisors should pass legislation to go on record opposing federal drug policy and urging an enlighted program of decriminalization, similar to that which was recently approved in Switzerland.*

Private Funding

Community-based AIDS organizations that depend on private donations for all or much of their funding report that fundraising has become much more difficult as the public has developed the perception that the AIDS crisis is diminishing.

In addition, one of the major sources of private funds for AIDS organizations in the past has been bequests, which are now greatly reduced due to the decrease in AIDS deaths.

As a result, some programs have had to cut back on services and benefits; some are threatened with having to cease operations entirely.

The general public, as well as corporate and foundation grantmakers, need to understand that the need for funding has not diminished with medical progress, but in fact is increasing as the number of persons living with AIDS increases.

Recommendation:

1. *We urge the Mayor to issue public statements in the media, appealing for continued financial support of AIDS community-based organizations, and to use his influence with local corporations and foundations to maintain or expand grant levels.*

Prison Issues

Sheriff Mike Hennessey and other city officials should be commended for the progressive approach taken to AIDS issues in San Francisco's jails. Prisoners and detainees in San Francisco jails receive better medical care than in the state prison system. The City's jails distribute condoms to inmates, one of only six jurisdictions in the country to do so. We recommend several improvements to San Francisco's positive approach in the jails:

Recommendations:

1. *San Francisco's criminal justice system should establish an innovative sentencing and compassionate release program to assist criminal defendants and county prisoners with HIV/AIDS to 1) have their charges reduced due to their medical condition; 2) be sentenced to community drug treatment programs rather than the state prison system; and 3) to recommend and release terminally ill prisoners on a systemic basis before trial so that they are not sent out into the state prison system.*

2. *The Sheriff, with the support of other city officials, should initiate a pilot bleach distribution program for all inmates. Upon entry to San Francisco jails, all prisoners would be given a packet of bleach, along with instructions from public health outreach workers to prevent the transmission of HIV, Hepatitis C and other communicable diseases. This program would be the first in this country, although Canada and many European countries have similar programs in place.*

Committee Members

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Andy Williams, *Co-Chair*
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The Future of Federal AIDS Funding

A strong funding commitment from the federal government is essential for San Francisco to respond effectively to the many challenges posed by the HIV and AIDS epidemic. This section will describe the federal response to date and assesses the budget prospects for the next five years.

The first cases of AIDS were reported by the Centers for Disease Control and Prevention (CDC) in 1981. That year, Congress began providing funds for surveillance activities at the CDC and for research activities at the National Institutes of Health (NIH). *Figure 1* demonstrates the history of AIDS funding from 1982 through 1998.

As the graph illustrates, the federal response during the Reagan Administration was halting and inadequate. Although federal funding increased during the Bush Administration to become more commensurate with the threat posed by the epidemic, this was due largely to Congress providing funds not requested by the President.

In the first ten years of the epidemic, federal funding outside of traditional entitlement programs was limited to research, surveillance and prevention activities. Beginning in 1991, despite the strong objection of the Bush Administration, Congress funded the Ryan White CARE Act to provide financial assistance to cities and states for medical care and support services for people with HIV disease. Then in 1992, again over the objection of the Bush Administration, the Congress began providing funding to cities and states for Housing Opportunities for People with AIDS (HOPWA).

Although people with AIDS receive services through a variety of entitlement programs, particularly Medicaid and Supplemental Security Income (SSI), it is research, prevention, patient care and housing programs which are subject to the annual battle over domestic spending priorities. In 1998, federal spending on these four major AIDS-related programs will exceed $3.6 billion.

Table 1 provides a summary of federal funding from 1991 through 1998 for these major AIDS-related programs. *Table 2* provides a summary of the funds received in the City of San Francisco over the same eight years under each of these federal programs. This table speaks to the critical importance of federal funding to the City to allow an adequate response to the local challenges posed by the epidemic.

AIDS Research

AIDS research is now 12% of all NIH funding -- $1.6 billion -- second only to cancer in terms of annual spending. The largest increases in AIDS research funding came between 1988 and 1994 when Congress added funds to respond to the public health crisis and scientific opportunities identified by NIH scientists. Since 1994, when Republicans gained control of the Congress and thus the appropriations process, AIDS research has not received a specific earmarked appropriation. In the last three years, the increase in funding for AIDS research has been the same as the growth in NIH spending overall.

Significant federal investment in biomedical research has paid off in terms of a better scientific understanding of HIV, which in turn has led to far more effective treatments for HIV disease. Yet, the success of AIDS advocates in securing increased funding for AIDS research has not gone unnoticed. Indeed, it has precipitated a campaign by other disease groups to shift resources to fund studies of diseases that affect a greater number of Americans. The pressure from other disease groups on Congress has been intense, prompting it to ask the Institute of Medicine (IOM) to study how NIH goes about setting research priorities.

It is not clear how this dynamic will play itself out within Congress or within the decision making process of the NIH itself over the next five years. If the "AIDS is getting too much" faction is defeated and NIH continues to set the priorities for biomedical research, then AIDS research will likely grow at no more than the overall growth rate in NIH funding. However, since both the Clinton Administration and the Republican Leadership in Congress have identified increasing investments in biomedical research as a priority for the next five years, merely growing at the same rate as NIH overall could offer the potential for significant new opportunities in AIDS research.

San Francisco benefits enormously from the AIDS research funding. The University of California, San Francisco, is the largest center for AIDS research outside the NIH itself. More than $50 million federal dollars will support over 200 research programs in San Francisco this year, creating opportunities for participation in clinical trials and supporting the City's overall HIV programs. These research funds enhance the ability of San Francisco General Hospital to deliver state-of-the-art care, contributing to its being the highest rated center for HIV care in the country according to *US News and World Report*. The partnership between the research community and the City continues to enrich all aspects of the San Francisco response to AIDS.

HIV Prevention

While the federal response to AIDS research has generated many successes, the federal response to HIV prevention has been problematic. The American public understands the importance of preventing the further spread of HIV. In 1986, the Institute of Medicine described the federal response to AIDS on the prevention and education fronts as "woefully inadequate." A decade later, the federal response to funding HIV prevention continues to pale in comparison to the threat of HIV. Preventing new HIV infections means enacting policies that upset certain small, but vocal constituent groups. Good examples of such policies are the need for explicit sex education, condom distribution and clean needle exchange programs.

Although science has demonstrated clearly that prevention programs can change risk behaviors and save lives, HIV prevention does not have the same level of political support as AIDS research or patient care programs. Uninfected people have not organized to demand more HIV prevention services. It is much more difficult to organize support for programs to avert infection and theoretically save future lives when the needs of the already infected are so concrete and compelling. Yet, in managing a comprehensive response to the HIV/AIDS epidemic, preventing new infections must be a priority.

San Francisco recognized the importance of HIV prevention early in the epidemic. The City, working closely with community groups, implemented the most comprehensive prevention campaign in the country. Dramatic reduction in the number of infections in 1984 translated into a precipitous drop in the number of new AIDS cases in 1994. Yet, as San Francisco has also learned, prevention is an ongoing challenge where the needs and priorities change over time.

Leadership from San Francisco has helped reform our national approach to HIV prevention through the development of the local HIV community planning process. Under this program, the CDC provides funds to state and local health departments to conduct local need assessments and involve affected communities in a planning process to set priorities for HIV prevention programs. This approach has placed greater emphasis on targeting specific interventions to individuals and groups at highest risk of infection.

In 1997, the City received $8.2 million from CDC to assist in planning and conducting local HIV prevention activities. State and general funds were added to bring a total to $10.2 million for prevention programs. Figure 3 illustrates how prevention funding has been distributed by intervention.

While in other jurisdictions, the bulk of funding is used for clinic-based HIV testing and counseling this accounts for only 22% of local funding. The greater emphasis has been placed on venue-based outreach programs and behavioral models of risk reduction, including group and individual risk reduction programs.

The HIV Prevention Community Planning Group has identified and prioritized twelve behavioral risk populations and is working with more than a dozen community-based groups to carry out a wide range of HIV prevention interventions. The use of local funds has allowed the support of needle exchange programs, which unfortunately can not yet be supported with federal funds.

The prospects for HIV prevention funding over the next five years are not bright. The Clinton Administration is unlikely to request any additional funding for the next fiscal year for CDC HIV programs. Some Republicans question whether moving funds from HIV prevention to preventing chronic diseases such as heart disease and diabetes would not be a better use of limited CDC resources. As with research funding, how Congress resolves this concern will determine the future of HIV prevention funding.

Ryan White Program

The Ryan White CARE Act was authorized in 1990 to provide a variety of medical and support services to people living with AIDS. The program provides grants to 49 metropolitan areas with very high numbers of AIDS cases for outpatient and ambulatory health and social support services. The program also provides comprehensive care grants to states for the operation of HIV service delivery consortia, for the provision of home and community-based care, for continuation of health insurance coverage for infected persons, and for purchase of therapeutic drugs.

In addition to these direct grants, the Ryan White Act also provides discretionary grant programs for community health centers, for demonstration projects to improve care for HIV-infected children, adolescents, pregnant women and their families, for reimbursement to dental schools for providing HIV-related dental care, and for centers to train health care personnel who care for AIDS patients and develop model education programs.

San Francisco played a leadership role in the development of the Ryan White legislation. One of the goals of the legislation was to replicate the successful "San Francisco Model" of outpatient care in other parts of the country. The City and the many community-based groups in San Francisco

have been a vital part of the annual mobilization in support of increased Ryan White funding.

In the last two years, the Ryan White program has struggled to respond to the challenge of providing new treatment opportunities to people with HIV who could benefit from such new therapies. The new opportunities have shifted resources within the program from care of end stage disease to providing combination therapies and primary care to as many people as possible. In the last two years funding for the targeted AIDS Drug Assistance Program (ADAP) has increased from $50 million to $285 million. Yet, even this increase is inadequate to meet the increasing demand for these expensive drugs.

Nationally, the number of annual AIDS deaths has decreased by 23% since 1995, while the number of people living with an AIDS diagnosis has increased by 11%. At the same time, the number of people with HIV for whom treatment is recommended under new treatment guidelines has increased the strain on the ability of the health care system to respond.

Funding for the Ryan White program is likely to continue to increase over the next five years, although the extent of growth will be limited by the balanced budget agreement. This year Congress has provided $1.15 billion for the Ryan White programs. The President will be requesting an increase of $165 million or 14 % for the next fiscal year bringing total funding to over $1.3 billion. The program has strong bipartisan support and is likely to continue as a domestic funding priority.

This year, San Francisco is receiving $36.4 million in direct emergency assistance and an additional $1.1 million through the state grants for comprehensive care. *Figure 2* illustrates the allocation of Ryan White funds in San Francisco in 1997. The largest part of these funds is used for primary outpatient care and other health services such as dental, home-health, hospice, and rehabilitation care. The second largest part of these funds is used for mental health and substance abuse treatment, which are often necessary for individuals to adhere to complex medical treatments. The remainder of the funds are used for important support services including housing, nutritional support and case management.

While the federal funds have increased significantly over the last several years, the direct Ryan White Title I funding to San Francisco has decreased slightly from a peak of $40.6 million in 1994. This is because half of the emergency assistance funds, which are awarded by formula, are based on the annual number of AIDS cases, which has been declining since the epidemic peaked here in 1992. Fortunately, the reauthorization of the Ryan

White Act included a provision limiting reduction to any jurisdiction in any year to one percent. The second half of the emergency assistance funds are awarded based on a competitive grant review process. Because the City submits such exceptional proposals, the overall level of funding under Title I has remained high.

Providing financial assistance with the high cost of combination therapies remains a very high priority. The AIDS Drug Assistance Program (ADAP) is part of the Title II of Ryan White program. Beginning this year, the cost of the program will be administered directly by the state rather than the City. Spending for ADAP is expected to increase from $90.3 million in 1997 to $126.1 million in 1998,with 44% being state funding. In San Francisco, the cost of this program increased from $3.5 million in 1996 to $13.7 million in 1997 and is estimated to climb to $19.2 million in 1998.

Housing Opportunities

Securing adequate housing for people living with HIV has been an enduring problem for people living with AIDS. The challenge is particularly acute in San Francisco, one of the most expensive housing markets in the country. In 1990, Congress authorized the Housing Opportunities for People with AIDS (HOPWA). The program provides grants to states and cities with over 2,000 cases of AIDS for a variety of housing activities, including information services, resource identification, transitional housing, long term rental assistance, support services and funds for building or remodeling facilities.

As with other major federal AIDS programs, San Francisco served as a model for the development of the legislation and also provided the political leadership to pass the legislation. Congress has provided $204 million for HOPWA in 1998. The five-year outlook for funding is problematic because the budget agreement calls for significant reductions in such domestic discretionary programs. The authorization for the program has also expired and it is not clear how the Republican led Congress will approach this problem.

Figure 4 illustrates the allocation of cumulative HOPWA funding through 1997. Capital projects have involved remodeling and construction costs associated with seventeen AIDS housing projects. Support services include contracts for Peter Claver, Leland House, Larkin Street Youth, Maitri, and Walden House. The remainder of the funds is used mainly for direct rental assistance.

San Francisco will receive $7.2 million under HOPWA in 1998 through a grant to the Redevelopment Agency. This is a reduction from the high point of funding of $10 million in 1994. Again, the funding is based on a formula using number of AIDS cases reported to the CDC, which peaked here in 1992. Because reauthorization has not taken place to limit the number of new eligible jurisdictions, the increased funding at the federal level is spread over more and more jurisdictions each year.

The Federal Budget Outlook

Since the Clinton Administration and the Republican Leadership in Congress reached an historic five-year balanced budget agreement last year, the budget outlook for federal AIDS spending has looked rather grim. This budget agreement called for a significant reduction in taxes and major reduction in spending for domestic discretionary programs. In fact, the five-year budget called for a sixteen-percent reduction in spending for public health programs. Under these budget requirements, a freeze in federal AIDS spending over the next five years would be a victory.

AIDS advocates expressed great concern over the budget agreement and were very critical of the Clinton Administration for dropping AIDS as a protected presidential priority in the budget negotiations. In fact, the Presidential Advisory Council on HIV/AIDS recently expressed concern that "progress in the federal response to AIDS has stalled in recent months, contributing to a sense of diminished priority of AIDS issues in the President's second term." The Council was particularly critical of Administration for its failure to support adequate funding for the ADAP in the last year.

Since the budget agreement last year, the budget climate has changed significantly. Rather than ending the year with a budget deficit of $120 billion, the final figure was only $22 billion. Rather than projecting a balanced budget by the year 2002, the budget is now projected to balance this year or next. Attention has now shifted to discussions of how to spend a potential budget surplus. Thus, the overall budget outlook has changed.

While AIDS advocates had braced for no significant increases in the President's budget request, the Administration recently announced it would request significant increases for both Ryan White programs and NIH AIDS research. Unfortunately, HIV prevention was not part of the presidential plan. Nonetheless, at least for fiscal year 1999, the budget outlook looks better. The five-year outlook will depend entirely on how the future negotiations on budget priorities are resolved between the Administration

and the Republican Leadership in Congress. Of course, this concern will also be part of the political mix surrounding the mid-term elections of 1998.

– **Steve Morin, Ph.D.**
AIDS Research Institute, University of California, San Francisco

Figure 1

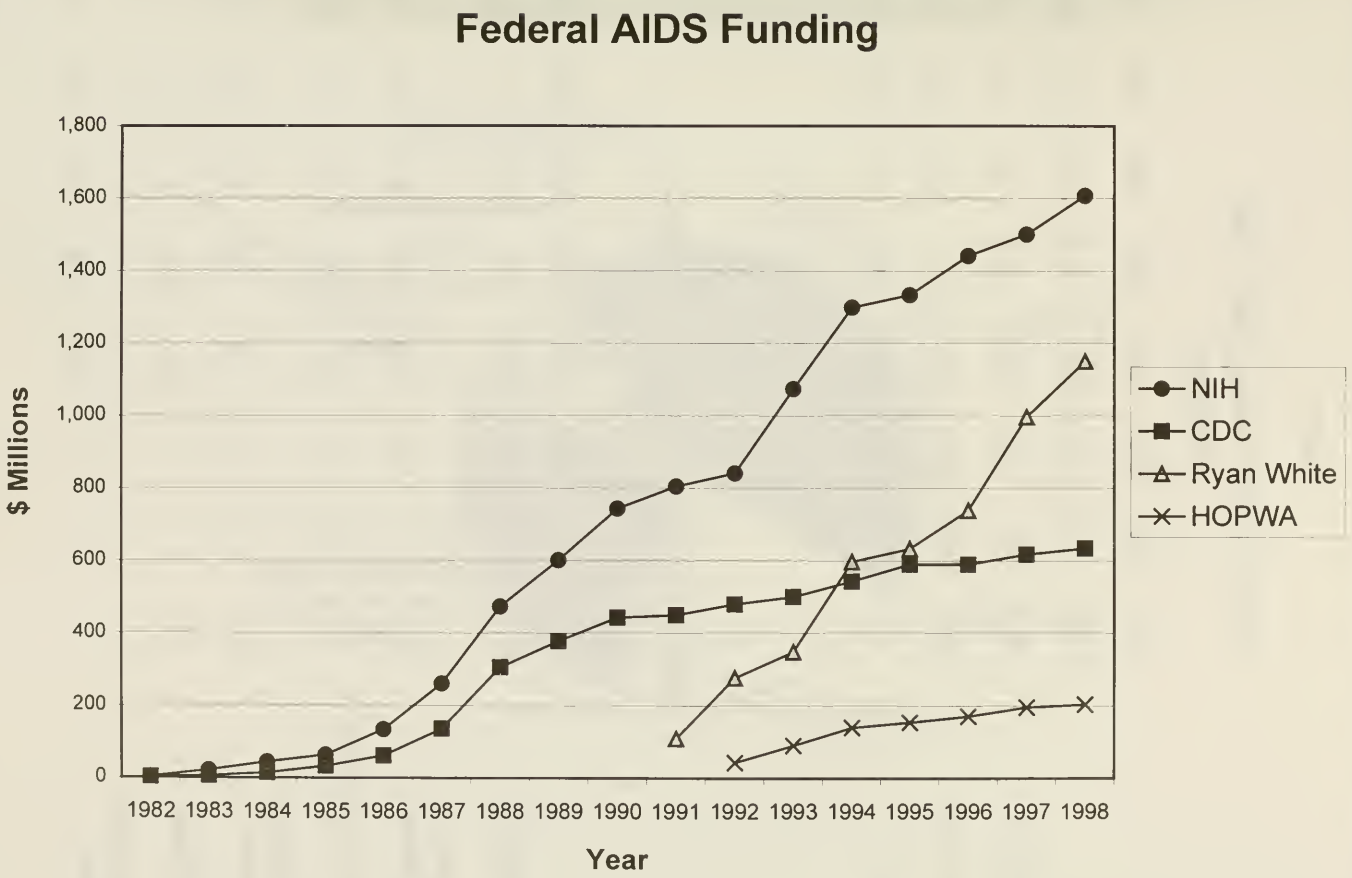

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Table 1

Federal AIDS Funding 1991 - 1998
(in millions)

	1991	1992	1993	1994	1995	1996	1997	1998
NIH	804.6	841.0	1,074.0	1,299.0	1,333.4	1,441.9	1,501.0	1,608.0
Ryan White	109.2	276.1	348.2	597.4	633.0	738.5	996.3	1,150.2
CDC (AIDS)	449.5	480.1	500.5	543.3	589.8	590.0	617.0	634.3
HOPWA	-	42.9	90.0	140.0	153.9	171.0	196.0	204.0

Table 2

Federal Funding to City of San Francisco
(in millions)

	1991	1992	1993	1994	1995	1996	1997	1998
NIH Research	24.1	23.1	36.8	46.8	48.1	48.3	51.7*	55.3*
Patient Care								
Ryan White	13.3	19.7	27.9	40.6	33.3	36.4	38.5	37.5
AIDS Drugs (ADAP)	2.4	1.2	2.3	2.5	2.2	3.5	13.7	19.2*
CDC Programs								
Prevention	6.0	6.1	5.4	5.9	7.5	7.5	8.2	7.7
Surveillance	1.9	2.1	1.9	2.0	2.0	1.7	1.1	1.4
Housing (HUD)								
HOPWA	-	3.1	5.7	10.0	9.8	7.4	7.9	7.2

* estimate

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Figure 2

San Francisco Allocation of 1997 Ryan White Title I Funds

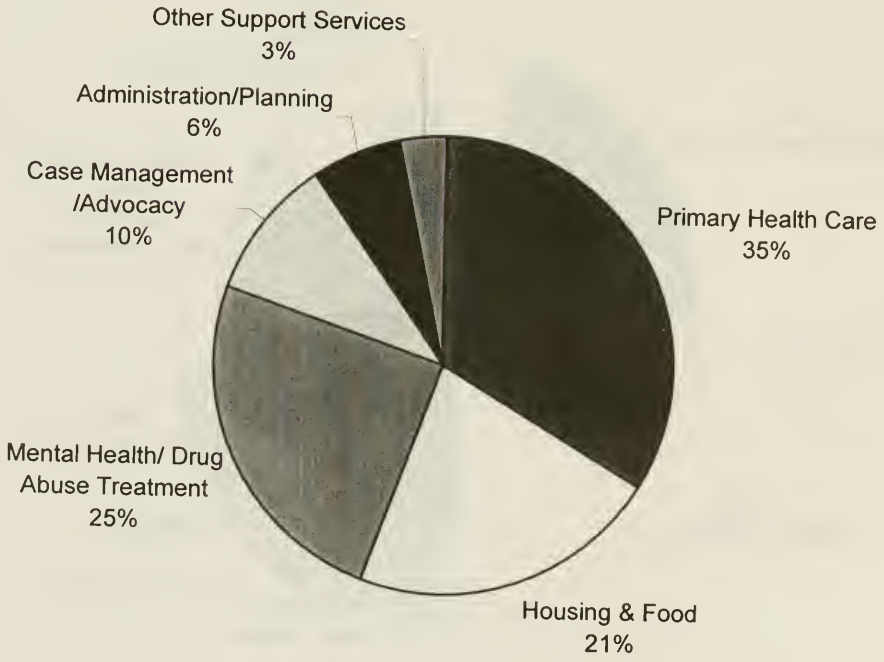

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Figure 3

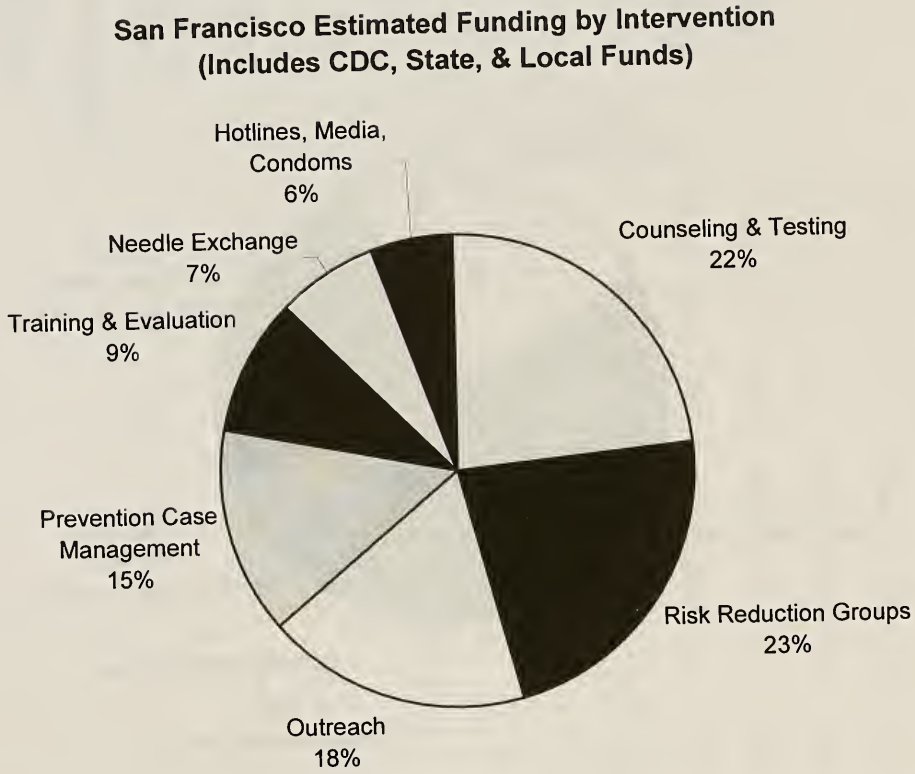
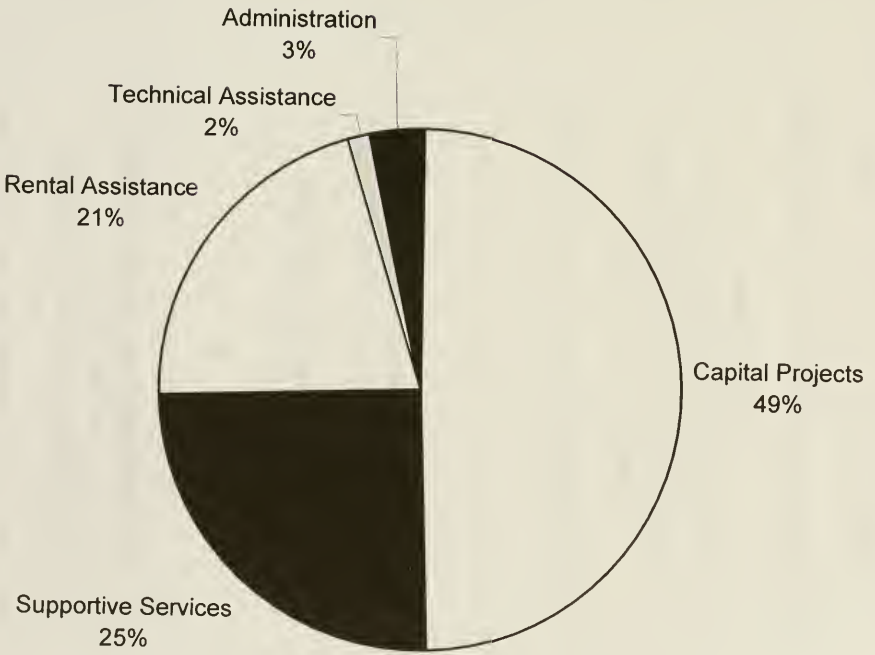

San Francisco Estimated Funding by Intervention
(Includes CDC, State, & Local Funds)
Hotlines, Media, Condoms 6%
Counseling & Testing 22%
Needle Exchange 7%
Training & Evaluation 9%
Prevention Case Management 15%
Risk Reduction Groups 23%
Outreach 18%

Figure 4

San Francisco HOPWA Funding - 1997



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After the Summit

The Mayor's Summit on AIDS and HIV
will be video taped for later broadcast on

CITYWATCH, Cable Channel 54

San Francisco's government cable access channel

Program Times:
Morning Session: January 28, 9:00 am
and February 1, 11:30 am
Afternoon Session: January 28, 8:00 pm
and February 1, 6:00 pm

For additional program times, call 557-4293

This report, as well as the oral presentations at the Summit
will be available on-line at

http://hivinsite.ucsf.edu

Congresswoman Nancy Pelosi
invites you to a
Town Meeting on HIV/AIDS

Join Rep. Pelosi for a discussion on the Federal commitment
to HIV/AIDS research and prevention and the implications
for San Francisco

Saturday, January 31
10:00 am
Everett Middle School
450 Church Street (between 16th and 17th Streets)

Comments

We welcome your comments on this report, the Summit or related issues that you believe should be considered. Public comments will be compiled and published in the final Summit Report, to be issued this Spring.

Name _____

Address _____

City _____ State _____ Zip _____

Please attach additional sheets as necessary.

Mail to: Mayor's AIDS Summit, 401 Van Ness Avenue, Room 416, San Francisco, CA 94012.

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